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ABSTRACT

The advocacy role of state developmental disabilities councils is examined in the monograph. It is explained that the material was gathered from a 1974 conference in Winter Park, Colorado. Topics addressed include the potential for advocacy, a personal perspective on developmental disabilities from a cerebral palsied adult, planning and evaluating council action, the role of consumerism, regionalism, revenue sharing, public awareness planning and development, legal developments, legal rights, and deinstitutionalization. (CL)

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ADVOCACY:

A Role for DD Councils

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PREFACE

The material presented here was developed as part of a National Conference on Initiative Functions of Developmental Disabilities Councils held in Winter Park, Colorado, June 11-14, 1974. It was organized by the Developmental Disabilities Technical Assistance System (DD/TAS) for the training of Developmental Disabilities Council chairpersons and staff directors from nine states. One of the major goals of that conference was to obtain the assistance of those participating in the conference in refining the material so that it would have more value to Council chairpersons and staff directors across the country. This volume is the result of that process.

One of the innovative aspects of the conference, which some of the participants thought should be shared, was the structure of the conference itself. That information is included in Appendix 1.

Many people assisted in the planning, development and implementation of the conference and later work on the materials. There is no way to list the names of all who helped and contributed to the success of a truly shared effort. A committee of the DD/TAS staff assumed responsibility for coordinating the development of the conference. That committee, chaired by Jim Paul, included Dan Davis, Jo Lowe, Paula Hammer and Ron Neufeld. The entire DD/TAS staff shared the work and responsibility for the conference. Jo Lowe, Grant Wolsiagel, Monica Hedgecock and Anita Buie made special contributions to the success of the conference. Each participating chairperson and staff director made their own individual and important contribution without which there would have been no conference. The consultants were outstanding. (Consultant and participant names in Appendix 2)

The material in this monograph really belongs to all of these people. The authors assumed responsibility for putting it together. In that effort the work of many is also acknowledged. Zena Harvley and Pat Trohanis are very high on that list.

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Advocacy Potential

The purpose of this brief paper is to set forth a point of view relative to Developmental Disabilities Councils which forms the philosophical basis for considering the advocacy potential of Councils. That potential derives from the flexibility available to Councils in deciding how to act on their mandate to provide comprehensive planning relative to developmental disability services. Within the constraints of their own accountability, Council decisions must be based on an analysis of two sets of issues: (1) those having to do with the needs, rights and total welfare of the developmentally disabled person and (2) those having to do with the organizational problems of service delivery. The Council's organizational structure and identity must be fashioned out of an adaptation of its own value system to the particular characteristics of the ecology of the state government (administrative, legislative, and judicial) in which it is to function.

The DD Council has enormous potential as a unique structure in state government for improving the total system of service delivery for persons who are developmentally disabled. That potential can be developed if the Council is able to: (1) generate, specify, and organize for effective action its own convictions and beliefs,

relative to the problems of serving the developmentally disabled; (2) develop a leadership and operational style that has workable diplomacy in that state's organizational/bureaucratic ecology, and (3) acquire the technical competencies necessary in order to efficiently and effectively implement its intentions and to interact successfully with other organizations. The advocacy of the Council is evidenced in two ways: (1) the value system or beliefs it adopts and (2) its own actions which give witness to those values.

The organizational ecology, policies and guidelines of agencies, existing legislation, resources and idiosyncrasies of agency leadership are natural constraints for the Council's development. They are, however, not fixed boundaries for either vision or the identity of the Council. They serve more to assist in the political and bureaucratic guidance of the Council, not in fixing its course or determining its advocacy mission. These constraints can become the focus for the development of some of the Council's goals.

The Council does have alternatives in defining and seeking an advocacy course. Those alternatives, neither formulated nor implemented in a vacuum, must be developed relative to a set of standards, criteria or values. What the Council stands for causes it to act significantly. Believing in something that must be accomplished or changed puts the Council in a volitional as opposed to a deferential or passive mode. Given the ambiguity of the legislation and regulations, those convictions or beliefs can properly be derived from two sources: (1) the client and (2) the care-giving system.

The client, the developmentally disabled person, has constitutional rights as a citizen. Denial of any of those rights compounds the disability. Those rights must be secured, especially in those instances where the disabled person is either not able or not permitted to rise to his own defense.

The developmentally disabled person has a right to live in his own community. If rejected by his own family, he has a right to resources for a decent life

without compromising his own personal integrity.

The developmentally disabled person has a right to pursue a life beyond stigma. This means having an educated citizenry, an accommodating physical environment, alternative resources which are not characterized by demeaning labels or exclusive incompetency criteria for participation, and an advocate to monitor his well-being and to assist in increasing productive and adaptive interaction between the developmentally disabled person and his environment.

The developmentally disabled person has educational, psychological and medical needs which must be met appropriately, sufficiently, and on time. The developmentally disabled person has a right to appropriate educational and treatment resources. No sub-human or even sub-standard environment -- physically, socially or morally -- can be rationalized as acceptable.

The care-giving systems are, themselves, a source from which we can extract information for developing the purposiveness of the DD Council. Care-giving systems have become large, complex, bureaucratic structures. Therein lies most of the work of the Council.

Bureaucratic systems can become encrusted with patterns, ritual and dynamics that contribute to their own survival. "Caring" is not a central function. The client is a commodity. Major decisions are made at the point in the bureaucracy farthest from where the client is located. There is usually not a good system for monitoring the well-being of the client. The system has not done well in monitoring and holding itself accountable for client welfare and contributing to client achievement. Data regarding what happens at the level of the client receiving service changes by the time it reaches the apex of the bureaucracy where decisions are made. Bureaucracy is programmed for coordinating and controlling, not for being coordinated and controlled. Each bureaucracy tends to seek its own level of activity, its own character and style and to establish and defend its own turf. Energy required for survival is taken off the top of the energy available. Remaining

energy is invested in constructive, developmental, and client-oriented goals. Large bureaucracies are characterized by excessive nonproductive costs, inefficiency, rigidity, closedness, and resistance to leadership and change. Rational planning and decision-making have not been characteristic features of large bureaucracies.

The important roles and functions of DD Councils are as numerous as the needs and rights of the developmentally disabled person. The ultimate concerns of the Council must be the rights of the developmentally disabled person that are denied. Each Council must fashion its own beliefs and convictions out of the problems and the possibilities of the organizational/bureaucratic ecology in its own state. Its intent is to see to it that the rights of the developmentally disabled person are not denied and that these rights need not -- must not -- be compromised as the Council develops its own style and strategies for becoming an effective adaptive component of the state system.

The following statements illustrate the kinds of beliefs or values that could constitute a creed for a DD Council as an advocacy mechanism in state government.

1. Councils should adopt an initiative posture, actively advocating for the interests of the developmentally disabled person.
2. Councils should promote the concept that human rights and constitutional assurances undergird all program and environmental standards.
3. Councils should promote the freedom and freeing of the developmentally disabled person.
4. Councils should insure that the dignity of the developmentally disabled person is not compromised in the process of providing services.
5. Councils should maintain a debureaucratized perspective on the developmentally disabled person, his needs and the resources he is actually receiving.

6. Councils should become active agents in planning for and insuring accountability to the developmentally disabled person.

7. Councils should promote a structure whereby decisions regarding the lives of the developmentally disabled person are made as close to the person as possible (and by that person wherever possible).

8. Councils should insure a "fit" of data on the developmentally disabled person and the realities of his or her life.

Each Council must develop its own list of beliefs. The process of Council members making their concerns and beliefs known to each other and then to all sectors of the human service bureaucracy in their state is itself a powerful advocacy activity. What we believe is what we wish to represent organizationally and programmatically. The DD Council is free to develop an advocacy posture: philosophically -- what it believes; organizationally -- the structure for implementing those beliefs; and programmatically -- the specific instruments by which those beliefs are exercised.



Council as Advocate

The recent conceptual evolution of advocacy has been thwarted by confusion in the area of definitions. Advocacy was popularized several years ago when Federal funds were released to launch a number of experimental advocacy programs. Since that time a large number of programs and projects bearing an advocacy label have appeared. It is the writer's opinion that a close examination of those activities labelled as advocacy would fail to produce a unique theme that would distinguish them from many other human service enterprises. The question then must be raised: what is unique about advocacy?

To begin with, advocacy broadly considered is a set of beliefs which result in action aimed at defending, maintaining or promoting a cause. Advocacy activity interacts both with individuals and with the systems that have been created to serve individuals. From an individual perspective, advocacy involves acting in behalf of, or pleading a cause for another. It may take the form of an able person fighting for someone who is not able to fight for himself, maintain his cause or protect his own human rights. The uniqueness of an advocacy perspective is perhaps most clearly visible at the point where advocacy interacts with the systems that exist to serve handicapped clients. It is the advocate's

belief that a program should be accountable to the clients it serves. The effectiveness of a system should be measured by its responsiveness to client needs in contrast to system maintenance needs or the convenience of a system's staff. An advocacy perspective starts with the client and attempts to examine services through the eyes of the client. The orientation of the advocacy approach to the human rights of the individual client is so strong that the advocate's style might be characterized as zealous. An advocate is fanatically devoted and partisan to his client. If need be, an advocate is willing to fight for a cause in behalf of his client despite resistance and intimidation from the system.

Advocacy as an individual activity is as old as the human race. In fact, a very important dimension of child rearing is directed toward training a child to be an advocate for himself. For an individual to successfully enter adulthood implies that he has attained a relatively high level of independence. That means, in part, that he has become a self-advocate. One aspect of normalization training for handicapped persons involves helping them to reach their highest possible level of independence or to increase their ability to advocate for themselves.

Beyond an individual, the family in our social structure is viewed as the basic advocacy unit. The family bears responsibility to its dependent young and handicapped members to engage in advocacy activities. In rural America, the family, the Church or a community was often highly successful in advocating for the needs of their respective memberships. It was often true that rural families lacked access to care-giving facilities for handicapped persons outside of their own communities.

In a small community, handicapped persons may have been known by all of its membership. The strengths and limitations of persons were likely to be known by everyone, and in many instances, community support was generated for the handicapped person and the family. Emotional support was available for the family, and corporate care was provided for the person as care was needed,

ranging from personal supervision to the supervision of work that the handicapped person could manage.

Along with the industrialization and urbanization of our social structure, we have witnessed a breakdown in family and community solidarity. With this breakdown, the capability of families, churches and communities to advocate for their members has been diminished. Given the size, complexity and impersonal nature of many of our human service arrangements, it is often impossible for even competent and highly independent individuals to advocate for themselves. Despite competence levels, individuals are often ruthlessly dominated by large organizations.

Due to the apparent breakdown of the informal, human advocacy procedures that have operated in the past, we are confronted by a need to identify some new advocacy approaches. In this paper, the clients needing advocacy are the developmentally disabled, a minority population whose cries are seldom heard in the political and bureaucratic streams of local, state and federal organizations. Unlike the informal, unstructured advocacy techniques of the past, the time has come to consider the value of promoting the concept of advocacy for the developmentally disabled as a social movement. Needed is a movement aimed at assuring the human rights of the developmentally disabled person; a movement aimed at rendering services accountable to their clients; a movement committed to identifying and providing support for effective advocates; and a movement geared toward a functional yoking together of individual advocates.

In order for advocacy for developmentally disabled persons to flourish as a social movement, several alliances are needed. Those alliances include: developmentally disabled consumers; non-handicapped advocates for developmentally disabled persons; professionals and non-professionals; programs in institutions and communities; a variety of fragmented categorical groupings; and finally, representatives from the public and private sector. The intention in this chapter is to explore the potential of Councils for the Developmentally Disabled to function as advocacy mechanisms within the system. It

will focus primarily upon the merger that is needed between the public and the private sectors or the alliance between advocates inside the system and advocates outside the system.

INTERNAL AND EXTERNAL ADVOCACY ACTIVITY

Two forms of advocacy activity have emerged at this point. They can be characterized as internal and external advocacy. Internal advocates work within the systems that support them, whereas external advocates receive support from sources that are independent from the systems in which they perform their advocacy activities. One major objection to internal advocacy programs is that advocates in the system lose too much freedom to act in an objective, unbiased fashion in behalf of their clients. "Whose bread I eat, his song I sing." To the extent that this adage is true, advocating within the system is a disadvantage. When client advocacy activity results in conflict between the advocate and the system providing his support, an advocate may feel pressured to compromise an ideal. It's difficult to bite a feeding hand. If a system resists the advocacy activity of the advocates it sponsors, it may employ a variety of "cooling out" tactics. For example, advocates may receive work assignments that create distance between advocates and their clients. The risk of system co-option or "cooling out" suggests that there may be an advantage for providing independent support for the work of advocacy to give assurance that the system in which the advocates work will not control them.

One of the advantages of advocacy from within the system is that advocates are likely to have greater access to information about programs serving their clients. External advocates tend to be adversaries of the system. System adversaries are often disliked by service providers and they are therefore denied access to the service delivery settings and to important sources of information. If advocates cannot monitor the delivery system directly, then the information on which they base their actions must be second-hand information. The actions and accusations of advocates must be based on accurate information. A rapid erosion of advocacy credibility will

result from actions and accusations based upon false information or incomplete data. System adversaries may be viewed as Quixotes tilting with windmills. They don't know the issues and they don't know the enemies.

Another important difference between internal and external advocacy concerns the tactics they employ. Internal advocates are likely to believe that human service systems can be renewed and that this renewal can be accomplished from within the system. When they are faced with a problem, their first approach is to bring about change by negotiation. Confrontation is a last resort.

It has already been pointed out that external advocates are often characterized by a strong negative system bias. They contend that our current human service systems are beyond redemption and must be dismantled. Their intent is to destroy and start anew. They view negotiation with the human service establishment as a waste of time and move immediately to confrontation. Caught up as they often are with their obsession to tear down the existing structures of the system, they sometimes overlook their advocacy goals and fail to foresee the injuries that their clients may suffer in the system dismantling process. Additionally, the external advocate may not be able to offer the support a client may need if existing services are withdrawn. They may see the problems, but stop short of providing solutions much like the terrier chasing a locomotive. What will he do with it when he catches it? There are many natural advocates and potential advocacy allies in the system. A wholesale condemnation of the system, all of its parts and all of its personnel, is likely to stand in the way of an alliance between the internal resources and an advocacy movement.

Another disadvantage of external advocacy programs is that they tend to be transient. Financial support is often small and short term. A single charismatic leader is often responsible for the genesis and direction of the program. Generally, a small band of highly committed persons work toward solving a small number of specific problems. When the problems are solved or appear insoluble, when financial support collapses or when the leader disappears, the movement is likely to vanish.

The foregoing polarization of internal and external advocacy activity is seldom witnessed in the extreme forms described. However the distinction between internal and external advocacy is a useful one in order to help Council advocates consider the strengths and weaknesses of the different approaches. Despite the differences between the internal and external advocacy approaches, it is likely that they would agree upon the problems facing the developmentally disabled persons. The differences between the two approaches concern the tactics they use. Obviously there are advantages and disadvantages to both internal and external advocacy approaches. For advocacy to become an effective social movement, it will be necessary to integrate the strengths from both approaches. This entails the development of an advocacy mechanism within the system that has a strong alliance with organizations from the private sector.

It is intended in this paper to examine the capability of Councils for the Developmentally Disabled to function as advocacy structures within the system at the level of state government. The role and functions of Councils as outlined by the federal legislation (P.L. 91-517) include a number of provisions that enable them to undertake advocacy responsibility for developmentally disabled persons. Among the legislative provisions that establish internal advocacy functions are: comprehensive planning for developmentally disabled persons, service coordination, and service monitoring. In order to plan, coordinate and monitor, Governor appointed state councils have been established. These councils include membership from several consumer groups and a variety of state agencies. An attempt is made in the following discussion to indicate the kind of advocacy activity that DD Councils can provide for developmentally disabled clients at the level of state government.

ACCOUNTABILITY AND MONITORING

As internal advocates for developmentally disabled persons, one of the functions of a Council for the Developmentally Disabled is to render the human service network, from the level of State agencies to the level of the service delivery network, appropriately account-

able to developmentally disabled persons. It is this writer's belief that over time, human service programs are often guilty of misdirecting accountability. That is to say, many public programs are self-serving and more responsive to the needs of their employees than they are to the public and their clients. In a democracy, the principle is generally accepted that the elected government and its administration must be accountable to the people. Accountability is a strong word. At the very lowest level it embraces the notion of a tie, an allegiance or a commitment. At another level, accountability means answerable to, responsible to and dependent upon. If state programs are answerable to and dependent upon the public, exposure to the public and openness is implied. In many instances, decisions in human service systems are made with the convenience of the staff in mind rather than the needs of the clients. Employees often find themselves answering primarily to other employees or working to maintain the system for staff convenience. Client needs become secondary. Staff centered programs are likely to be closed systems in the sense that they resist external investigations and are not open to the public. Exposure to the public might result in criticism or a loss of the privileges and advantages that staff centered programs provide.

When an employee in a public service program must make a decision between self-serving action or action in behalf of the clients, it is clear that the client should be served. Occasionally, however, public employees are confronted with making decisions between conflicting interests. In such an instance, a "right" decision may be more difficult to find. A "decide for yourself example" is presented below. Let's suppose it has been reported to an elected state official that state cars are being used for private purposes. One solution that has been proposed to prevent this abuse is that decals be placed on all state cars. Cars from a residential school for emotionally disturbed youth are identified with a state psychiatric hospital. On several occasions the students are embarrassed when riding in the marked state cars, and they are harassed by local youth because of their association with a psychiatric facility. In this instance the state official is faced with conflicting account-

ability. On one hand, the official may feel a need to protect the interests of the general public, who elected him, against the misuse of state property. On the other hand, the state official should feel a keen sense of responsibility for and accountability to the emotionally disturbed population entrusted to his care. It is this writer's opinion that the psychological and emotional welfare of the residents in the state school should prevail over the financial considerations of the political constituents. However, in situations such as the one presented above, the public official may choose to support a decision that is not in the best interest of the minority disenfranchised population. When this is the case, advocates are needed to help protect the rights and interests of the handicapped persons.

A variety of advocacy mechanisms are needed to assure appropriately directed accountability. Self-serving bureaucracies need to be confronted and state officials need support for making responsible decisions in favor of developmentally disabled clients (consumers). Aggressive support for state officials is especially necessary when decisions in favor of a minority group may result in a loss of political support from the general public. Developmental Disabilities Councils are in a position to provide support for advocates in the system. Councils also have the potential to assure properly directed accountability in the human service delivery system.

Next, several techniques are presented that a Council can employ to assure accountability to developmentally disabled clients.

One technique a Council can use to assure properly directed service accountability is to monitor human service programs. To monitor is to watch. One of the advantages of monitoring programs is that services often improve simply as a function of monitoring. Several investigations provide support for this observation. For example, Dr. O. Lindsley, who developed the precision teaching procedure, once attempted to identify a variety of factors that contributed to change in human behavior (1972). None of the interventions investigated appeared to make a difference. The single significant variable

that appeared to affect behavioral change was the process of data collection itself. In an experiment conducted by Dr. J. Reid, it was discovered that the accuracy of data collected by behavior observers increased when they were being watched (undated). Similarly, in their experiments with oppositional children, Dr. G. Patterson and Alice Harris discovered that interaction within family units changed when observers were present (undated).

The point is that in many instances it has been demonstrated that the behavior changes if subjects know they are being watched or monitored. With this in mind, perhaps improved or redirected program accountability could be accomplished if a variety of monitoring procedures were established to watch service providers. Perhaps developmentally disabled persons would be guaranteed their fair share of public resources if the decisions of elected officials and the activity of state agencies were monitored by mechanisms advocating for the developmentally disabled. At the service delivery level, perhaps monitoring service providers would result in more responsive programs for developmentally disabled persons. At the individual level, it is likely that monitoring would assure more effective use of existing services and provide information concerning the need for new programs.

There is no short cut to individual client monitoring. Although the most effective watching is provided by the members of a client's family, there are times when the family may not be fully aware of a client's needs, nor of the services that are available. For this reason the parents of handicapped persons should be trained to recognize client needs and be apprised of the resources that can meet those needs. In some instances, client monitoring within the family may not be sufficient. In the absence of support by trained professionals, some communities have successfully organized groups of volunteers that can function as extensions of the family. Once again volunteers cannot be expected to function successfully without substantial training concerning client needs and available and needed resources. Hence, it is this writer's contention that professionals must launch extensive recruitment and training programs aimed at mobilizing neighborhood and community based organizations, trained to

recognize areas of unmet client needs, and trained to identify and access available resources.

At another level, the quality of service-provision for developmentally disabled clients should be checked by program monitoring. Programs should be checked to guarantee that: the rights and interests of clients are protected; that the service provided is responsive to client needs; and that the physical facilities are designed in the best interest of the client. Substantial knowledge about human service programs is required at this level of monitoring. On one hand, program monitors must know how to identify program weaknesses. At the same time, they should be aware of program alternatives for service delivery. In this way, an advocate as a monitor can offer constructive criticism when program weaknesses are exposed and can negotiate change.

Despite industry's recognition of the need for quality control, monitoring has never been viewed as a necessary procedure for quality control in human service settings. Traditionally, the general public has invested blind trust in professionals and service providers to "do good" and has refused to get involved. To suggest the need for monitoring in the human service delivery system smacks of distrust. Service providers tend to recoil with defensiveness, suspicion and counter-proposals to "cool-out" the monitors. Yet the recent exposes of human abuses in institutional settings such as Willowbrook in New York and Parsons State Hospital in Alabama clearly indicate the need for program monitoring in residential settings. The periodic program reviews or site visits often sponsored by the state departments responsible for these programs are seldom adequate monitoring procedures. It is too easy for program staff to hide program weaknesses behind brief superficial investigations. Also the occasional inquisition of a dedicated newsman or a consumer organization will often result in employee routes and reorganization. But the renewal resulting from this kind of monitoring is often short lived.

A few institutions, recognizing the need for constant program monitoring, have been attracted to the concept of advocacy as a way to monitor their programs and assure service accountability to their clients. In one

such institution, a team of five advocates has been hired to monitor services provided for seven hundred residents. They are accountable directly to the Superintendent. When they encounter violations of resident rights or program weaknesses, the advocates set in motion a process of negotiation with the staff to correct the problems. If there is disagreement between the staff member and the advocate, or if the staff person fails to make program changes in the interest of the client, confrontation is used. Unresolved conflicts are taken directly to the Superintendent and the Human Rights Committee. The Human Rights Committee consists of institution staff, residents and the parents of residents.

Advocacy designs such as the one described above may have value not only for program monitoring but also for tracking clients on an individual basis to assure the appropriate provision of services. Program weaknesses are often exposed by this monitoring procedure. The problems of this design are the same disadvantages specified for all internal advocacy activity. The risk is co-optation or "cooling out." Furthermore, if the hiring of advocates is a decision that institution administrators are free to make, then institutions that most require monitoring services are likely to be the ones that will resist advocacy services. Ideally, advocacy in institutions should be externally accountable, and advocates should be paid from an outside source. One suggestion is that DD Councils establish local or regional councils to whom advocates would report. Finally, advocates as monitors must develop excellent data collection skills. It has already been pointed out that nothing can erode the credibility of advocacy activity with greater speed than false information.

Another technique for program monitoring that is currently in use is the application of program standards for community and regional institutions. Apart from standards developed by individual states for their own use, the standards for residential facilities and standards for community agencies developed by the Joint Commission on Accreditation of Hospitals are the most widely known and used. These standards are particularly useful for indicating program gaps and weaknesses.

The ombudsman model developed in the Scandinavian countries is another monitoring procedure for programs at the state level. Effective advocacy by ombudsmen requires the direct flow of information from clients to the ombudsman. When the ombudsman is confronted with unmet client needs or violations of client rights, an attempt is made to eliminate the cause of the unmet need or rights violation at the system level. Successful ombudsman activity calls for a substantial power base inside the system.

The need for client and program monitoring was recognized by the staff of Child Advocacy System Project, a neighborhood advocacy program conducted in Morganton, North Carolina. Two procedures were developed in this project, one, a procedure for monitoring individual clients (Pelosi, J. & Johnson, S. L., 1974) and, two, a procedure for monitoring programs (Holder, H. D., Pelosi, J., & Dixon, R. T., 1974). The individual monitoring procedure suggests a procedure for helping monitors to recognize when advocacy is needed and how to go about accessing resources in behalf of the client. The program monitoring procedure suggests approaches to identify program weaknesses from a client perspective, and suggests ways to render programs accountable to their clients.

An important consideration in service monitoring is the location in state government of the monitoring mechanism. Effective monitoring is unlikely to be effective outside of the agency in which the monitor is lodged. Also, unless the monitoring mechanism has substantial support from outside of the system, then it must depend entirely upon support from the chief executive in the host agency. The best insurance for effective monitoring is a network of councils extending from neighborhoods to counties to multicounty districts. These councils should involve citizens and have substantial support from the private sector. At present, the councils can look toward consumer or parent groups such as the associations for retarded children or some of the emerging noncategorical consumer organizations.

Despite the negative reception that the concept of monitoring is likely to encounter in human service

settings, service monitoring is an important aspect of assuring programs that are accountable to developmentally disabled clients. Monitoring should take place at all levels of activity ranging from the client to the service delivery system to the state agency. Monitoring sponsored by a system needs the unqualified support of the chief executive in the program or agency in which it is located, and monitoring outside of that agency is likely to be ineffective. The chances for effective monitoring are increased when the monitoring agency has support from the private sector. Finally, the results of monitoring need to be communicated to persons or organizations that can bring about change in those systems.

COMMUNICATION

The story is told of a farmer in Maine who had a telephone installed in his home. One night, while a neighbor was visiting with the farmer, his phone began to ring. Despite repeated calls, the farmer refused to answer his telephone. When asked why he failed to pick up his receiver, the farmer replied, "I had that damn thing installed for my convenience."

The human service delivery system cannot afford the luxury of one-way communication. Communication concerning citizen needs and problems must flow upward from communities to state program administrators. Some organization must then assume responsibility for apprising the public and legislators concerning the needs of developmentally disabled persons. Finally, the communication cycle is not complete until the public is apprised of the various programs and interventions that are created in response to client needs.

Since communication exchange concerning human service delivery is weak in most states, it is this writer's opinion that DD Councils might assume responsibility for establishing a comprehensive communication network.

At the level of state programs, communication between state agencies is essential in order that the Council accomplish the work of comprehensive planning and service coordination and if it is to influence human

services from an advocacy perspective. Change that can be accomplished through negotiation is likely to be more effective than change that is sought as a consequence of confrontation. Although all of the changes that may be needed to support the rights and interests of the developmentally disabled person may not be accomplished through negotiation, negotiation should be the first tactic employed. Confrontation should be a last resort. Negotiation requires communication. For this reason, Councils must set up a system of internal communication with all parts of the human service network at the state level that it hopes to influence.

Councils, as advocacy mechanisms, must also develop a system of information exchange between the public and the private sector. It is often true that state agencies and human service programs become closed systems because they try to hide program weaknesses. Inevitably program weaknesses that threaten program administrators are exposed to the public. In the wake of inquisitions and public exposures, employees are often fired and programs reorganized. Inquisitions and public exposures do not guarantee constructive changes. However, the public has a right to information concerning both the strengths and weaknesses of the programs that are supported by public funds. Given this knowledge, the public has responsibility for identifying and helping to provide solutions to the problems that face its programs. In this writer's opinion, this kind of openness with the public would tend to reduce the number of program investigations that result in shocking disclosures and public recoil. An appropriate function of Councils is to create a channel of communication between public programs and the public. Support from the private sector cannot be expected unless this kind of communication exists.

One strategy that a Council might use to provide information to the public concerning the delivery of services to developmentally disabled clients is to hire a communication specialist to communicate with the public through radio, television and the press. This person should be familiar with all programs serving developmentally disabled clients in his area, and he or she should know how to collect information concerning interactions

between the dispensers and receivers of care. The communication specialist would agree to spend a proportion of his time collecting data in human service programs. This data could then be reported to citizens in the community through newspaper articles, by news releases to television and radio stations and by public presentations to civic organizations and groups such as school boards or local parent and teacher associations. Citizens might be left to judge the nature of the interactions, but both negative and positive incidents should be reported.

It is interesting to speculate on the potential power of such a communication design to render the service delivery system more responsive to the public and its clients. Hopefully the public would become more knowledgeable concerning its programs and subsequently more involved. Perhaps Council action groups would organize to improve weak programs and support would be generated for the natural advocates that would be identified.

In order to initiate communication between state organizations and local citizens, the Council for the Developmentally Disabled in Utah conducted a series of televised public hearings. The hearings were held in seven different locations in the state. Persons were contacted in each county to disseminate information concerning the hearings and in order to make local arrangements. Letters announcing the meetings were sent to parents of handicapped persons, agencies working with the handicapped, State legislators, educators, and local and county officials. An attempt was made to avoid holding the meetings in facilities that were associated with a particular agency or program.

Six to eight members of the State Council conducted the hearings. All local citizens coming to the meeting were enrolled at the door and asked if they wished to speak. If so, they were invited to speak in the order in which they were enrolled. Because speeches were often spontaneous, tape recordings were made and stenographic notes were taken. Citizens who did not wish to speak were invited to submit written statements. After the citizens had spoken, raised issues or asked questions,

members of the council, agency personnel or legislators responded. Citizens attending the meetings ranged in number from fifteen to four hundred.

The recurring theme expressed at the hearings was the need for: increased money in special education; removal of the categories of mental retardation, learning disabilities, emotional disturbance, etc.; community training programs for the adult handicapped, especially the severely disabled not eligible for rehabilitation services; recreation and transportation; early diagnosis and intervention; parent training; community based residential alternatives in addition to State institutions; elimination of architectural barriers and access to information about services. It seems likely that knowledgeable professionals would have identified a similar list of needs. This kind of information should generate greater confidence among professionals in developing closer ties with citizens from the private sector.

The citizens who participated in the Utah hearings indicated that they were pleased to have a forum in which they could express their concerns, frustration and anger. They expressed a desire for more hearings in other parts of the state, especially in rural areas. During the hearings, parents of developmentally disabled persons were made aware of services in their area that they had not known of previously.

In addition to learning of needs from citizens, there were numerous advantages in the hearings to the Council itself. First, the Council's visibility was increased and its identity established, and second, the hearings resulted in improved communication between citizens and the Council.

In addition to the television coverage provided by the hearings, news releases were sent to local weekly newspapers and hearings in the more populous areas of the state were covered by daily newspapers with statewide circulation. The example cited contains many ingredients of a sound communication system. It included face to face encounter between citizens and ~~state~~ state-level program administrators. It encouraged private citizens to make

statements concerning needs as they saw them, and it gave the public an opportunity to ask questions of state employees. The information emanating from the hearings was disseminated, using television and the press. This would seem to be a good starting point for a sound and comprehensive communication network between state programs and local citizens. It could also provide initiative for the private sector to organize into action groups.

There are, of course, many ways in which communication exchange can be accomplished in a state. In some states, films, slide-tape presentations, and pamphlets or fliers are produced in order to disseminate information concerning client needs and services. Conferences and workshops are also conducted to bring together various interest groups and develop action plans.

In this writer's opinion, all of these activities are needed to assure complete information sharing among legislators, state agencies, consumer organizations, local government agencies, service delivery units and private citizens. The sharing of this information should not be left to chance. Rather, a careful design accounting for all parts of the social structure should be developed. At every level careful consideration should be given to the communication technique that is most effective.

THE PUBLIC ALLIANCE

It has already been pointed out that an effective advocacy system requires an alliance between the public and private sectors. Staff that are supported by developmental disabilities resources usually receive their salaries from a state agency. In this sense they are part of the state system and run the risk of becoming an additional agency of state government and being "cooled out" like any other internal advocacy mechanism. Unlike most state agencies, Councils for the Developmentally Disabled have the opportunity of relating to a council that consists of a variety of state agencies and several consumer agencies. Persons supported by developmental disability funds might be viewed as advocates within the system. The external advocates are private citizens working for and committed to the developmental

disabilities movement. Staff to the Councils should be viewed as seams in the fabric that bring together not only the public and the private sector but also the professionals or service providers and the nonprofessional citizen.

Historically, many parents of handicapped children have abdicated program responsibility and service delivery to professionals. Unfortunately, professionals alone have been unable to develop a system of services that adequately responds to the needs of handicapped persons in this country. On one hand, there are tremendous gaps between services, and many handicapped persons are not provided with the help and support they need. On the other hand, there are many overlapping services and scarce resources are wasted. Finally, many of the services that exist are inflexible and unresponsive despite information that indicates the need for change.

In some instances, professionals point out that the parents prefer to be relieved of responsibility for handicapped persons. Additionally, the general public tends to have a narrow range of tolerance for physical or behavioral variance. Professionals point out that even if public citizens wish to become involved in service delivery as volunteers, training them takes more time than it's worth. To the extent that these attitudes exist, one can understand the impulse of professionals to undertake program development and service delivery without involving parents or the general public.

If professionals were adequately serving the needs of handicapped persons without help from parents and other public citizens, we could accept their independence. But, since confusion seems to reign in the human service network and since we continue to be faced with many unmet needs, a strong case can be made for the development of sound linkages with the general public.

Areas of support that can be provided by the general public range from direct service, and individual and program monitoring, to participation on boards and political lobbying. In each of these areas, professionals should assume responsibility for recruitment, organization, and training.

In the area of direct service, it is clear that in the foreseeable future there will not be sufficient public resources to provide the kind of staff to client ratios that are necessary to adequately serve the needs of developmentally disabled persons. At the same time, the interest of parents and their potential for providing service has not been realized.

The Regional Intervention Program in Tennessee, as described in Chapter 5, provides us with an example of an excellent, cost effective program for emotionally handicapped children utilizing citizen participation. Parents applying to have their children admitted for treatment must agree to receive training and work in the programs for six months after their child has graduated. In this way, the project functions with only two full time staff members and backup consultation from professionals.

In Nebraska, a program of "live-in friend" involves a citizen advocate sharing an apartment with a retarded person who has been discharged from a residential institution. The occupations of "live-in friends" have included students, social workers, teachers, salesmen and secretaries. In most instances the "live-in friends" are not paid for their participation in the program. The "live-in friends" are benefactors (Heber and Dever, 1970) and teachers for their roommate in money management, shopping, use of public transportation, cooking, self-medication, use of telephones, and leisure time activities. It has been reported that the program is effective and economical (Perske, R. & Marquiss, J., 1973).

The concept of "benefactor" which undergirds the "live-in friend" originated from a study of persons discharged from a residential institution in California and who made successful adjustments to the cultural mainstream. In his research, Edgerton reports that the critical factor in community adjustment was the relationship of a retarded person to a benefactor. Benefactors helped them maintain: "(a) their self respect; (b) their ability to cope with the world; and (c) their ability to 'pass' for normal and to deny their mental retardation" (Edgerton, R. B., 1967).

The foregoing examples of citizen participation in direct service activity are presented to indicate the need to capture a large potential source of manpower. It is likely that there are many persons employed in private enterprises with a keen sense of altruism and no outlet for that impulse.

In addition to direct service activity, there are other areas of activity in which support is needed from the private sector. For example, action that is highly controversial should in most instances be undertaken by groups or persons from the private sector. Confrontation by staff members of the Council may result in a breakdown of communication in the system or may absorb so much staff time that the work of planning and coordination may be ignored.

At other times effective employees in state programs or working for the Councils may sometimes need protection from fickle political machinery. In this writer's opinion, human services need to be depoliticized. In the meanwhile protection from the political system is most effective when it emanates from the private sector. Support is also needed from the private sector in the area of lobbying and legislation. In the past, consumer organizations such as associations for retarded children have been most successful in obtaining the passage of legislation favoring developmentally disabled persons. While professionals can help in the work of organization and training, it is the weight of consumers that will produce political action.

Finally, it is becoming increasingly popular to establish boards with consumer representation. To the extent that this trend continues, Councils for the developmentally disabled need to recognize the need to provide training and education that enables consumers to function in more than token roles on boards.

CONCLUSION

Successful direct service activity is difficult to provide from the state level. One reason is that they are too far removed from the service delivery setting to be

adequately sensitive to the client needs. Among the products of state operated programs are the large regional institutions that exist across the country. In order to operate these institutions and in order to manage other aspects of service delivery from the state, top heavy administrative organizations tend to develop. In many instances planners, personnel departments and fiscal agents are not adequately in touch with consumers to know their needs. In order to exercise control from a distance, state agencies tend to develop rules, regulations and reporting procedures that seriously hamper program staff. Additionally, a large regional institution has its own impersonal routines to regulate the daily movement of staff and residents. The result is often a "top heavy", client insensitive system that spends the bulk of its energy and resources maintaining itself.

One alternative is to keep services small and numerous, in order that the services be located close to the consumers, thus enabling consumers to remain close to their natural environments. These services might then be made accountable to local boards. If the model of locally operated programs were adopted, the role of state agencies would shift from service provision to enabling and monitoring. State agencies would focus upon planning, resource acquisition, training, information dissemination, organizational work and monitoring.

To the extent that state agencies should be cautious concerning their involvement with direct service provision, this is even more true for Councils for the Developmentally Disabled. Persons and organizations with an advocacy perspective are often easily seduced into case advocacy activity. At this point it seems prudent to advise Councils to assume the role of "enabler" rather than the role of "doer" of advocacy activity. Since state agencies have the resources for service provision, the business of direct service should be left to them. The Council might work toward creating the kind of regional and local organizations that would eventually lead to decentralization and local service delivery, unifying all components of the system and bringing about an alliance between the public and the private sector. In this writer's opinion, service coordination is likely to

be accomplished with greater ease at the local than at the state level.

If Councils attempt to provide direct service to clients, they will find that their meager resources will soon be gone and they will have little to show in terms of ongoing activity. Additionally, the time required to engage the action needed for case advocacy would soon absorb all of the time of staff and Council alike, and no time would be left for planning, coordinating and communicating. Advocacy as direct service activity inevitably results in high profile controversial activity. Given the recency of developmental disabilities legislation and the recency of Council interaction with programs at the state level, high profile, controversial activity may result in a premature death of the Councils and the developmental disabilities movement. Council staff should spend their time in administrative enabling activity. As advocates inside the system, they should work toward developing an alliance with the private sector, the external advocates, and help them develop their skills in accountability procedures and service provision.

REFERENCE NOTES

1. Reid, J. B. "Reliability Assessment of Observation Data: A Possible Methodological Problem."
University of Wisconsin, Unpublished manuscript.
2. Patterson, G. R. and Harris, A. "Some Methodological Considerations for Observation Procedures."
University of Oregon, Unpublished manuscript.

REFERENCE LIST

- Edgerton, R. B. The Cloak of Competence: Stigma in the Lives of the Retarded. Berkeley, California: University of California Press, 1967.
- Heber, R. F., & Dever, R. B. "Research on Education and Habilitation of the Mentally Retarded," In H. C. Haywood (Ed.) Social-Cultural Aspects of Mental Retardation. New York: Appleton-Century-Crofts, 1970.
- Holder, H.D., Pelosi, J., & Dixon, R.T. How to Monitor Agencies Serving Children. Durham, North Carolina: LINC Press, 1974.
- Lindsley, O. "From Skinner to Precision Teaching: The Child Knows Best," In Jordan, J. B. and Robbins, L. S. (Eds.) Let's Try Doing Something Else Kind of Thing. Arlington, Virginia: Council for Exceptional Children, 1972.
- Pelosi, J., & Johnson, S. L. Advocacy for Your Child. Durham, North Carolina: LINC Press, 1974.
- Perske, R., & Marquiss, J. "Learning to Live in an Apartment: Retarded Adults from Institutions and Dedicated Citizens," Mental Retardation, 1973, II (5), 18.



Consumer as Advocate

I would like to share a few words with you which will hopefully make the word advocacy have additional meaning. I think I should first give you a very brief story about my life, something which I very seldom do. I was born in 1932. Because of my Cerebral Palsy, I went in the hospital in 1934 and didn't leave that same hospital until 1942. At the age of eleven or twelve, I still couldn't walk without some kind of physical support.

About this same time, I was sitting in my mother's yard one day, and I said to myself, "This is not for me. I'm going to have to make a life style for myself." I immediately began. I picked up a hand lawn mower that was leaning at the side of my dad's garage, and I started to mow the lawn. Soon I improved and began mowing other lawns for about two or three dollars a day. I wasn't making enough money to even pay for my shoes, because I wore out a pair every two weeks due to the way I walked. But I kept going. Over a period of 27 years, I built my own landscaping corporation in which I now employ seven men and two secretaries.

My life was also growing in other ways, for I married the most beautiful girl I ever saw. Needless to say,

she became an integral part in my accomplishments. Her name is Margaret. Six months before I got married, we bought an apartment house. Margaret, a polio victim from early childhood, and I lived there for six years. Later, I designed and built by own home specifically to make it as useful as possible for my wife. As stated, my wife is a polio victim and therefore, I wanted to build a house so that Margaret could get from one room to the next in a matter of seven steps. I built this house which my wife and I presently reside in, but that's enough about me and my personal life.

I want to share a brief thought with you, and that thought is that the most beautiful thing in estimation is a woman that is about to become a mother. What is more beautiful than the beginning of life? Nothing. No matter what you see out these windows there's no comparison. And that person--that child that comes out of the mother's womb has a right to live as normal as possible. And an institution is no place to begin. There should not be any barriers to blacken the room of that child's life. We all know that for some stupid reason, and they are stupid, there are barriers. And let me tell you something--these barriers are going to be lifted, because beautiful people like you are helping; how could they help but to be lifted? Nothing on earth can survive by itself--nothing.

I was sitting in my sister's yard one day and thought maybe I would just relax in a lounge chair and take a little snooze. So I climbed onto the lounge chair and was just about ready to close my eyes when my little nephew ran from around the front of the house. He stopped suddenly at the foot of my chair; he was staring at me. I pretended that I was sleeping and he came up to the side of the lounge and continued to stare at me. Then he moved away towards the back of the yard and I just peeked to see what he was up to. Albert stood beside a little hole in the ground and then he went back out to the front of the yard. He came back in about two or three minutes with a tree no taller than a foot high. He put this little tree into the hole, then he shoveled back the dirt around it. He then got

a little pail of water and put water around it. I got up from the lounge and I said to him, "Albert, what are you doing?" He said, "Uncle Frank, I found this tree in front of the yard underneath the front stairs and it wasn't getting any sun and I thought maybe if I took it and planted it in the center of the yard it would get the proper lighting." I said, "Fine, but that isn't enough." He said, "What do you mean?" I said, "Look, you go into the house, tell your mother you want two sticks and you want some string." And he did. He came out with the string and the sticks. I buried the sticks and tied the twine from the tree to the sticks. Then I said to Albert, "Now Albert, let the rains come, let the wind blow, that tree can now grow up into a strong tree." He looked up at me and he said, "Gee Uncle Frank, you're smart." I said, "No, when you get to be my age, you'll know this."

I feel that in order to be a good Christian you cannot do it by yourself. I cannot be a good Catholic if I do not go to Confession and receive the Sacrament once a month. It cannot be done by oneself, no way. When you are dealing with human lives you are dealing with people that are just as good as anyone. You are not just dealing with a contractor to build a bridge or a road, but these are people. They bleed just like you and me. They cry just like you and me.

Many years ago, when I was quite young, I once said to myself, "Why did God do this to me? There has got to be a reason." And by God, five years ago, I found that reason. I realized that because I have lived the experience of a handicapped person, I can put this knowledge to use to help others as an advocate. When people don't have the confidence they can make it because their handicap overwhelms them, it helps to know that someone else with the same problem has had success just as they can if they really try.

Education is no good without the sticks to support it. If one does not have the sticks of motivation, sensitivity, and intelligence, education is not worth a bean when it comes to helping underprivileged, handicapped people. It is too bad the criteria to obtain these sticks

do not often consider a fellow like myself, and there are many, many, more. It is too bad that we cannot enjoy a team like yours as full time members. It really helps you people, and makes your jobs easier by giving you better insight to the problems, although you don't totally know the problems unless you've lived them. You know the frustrations that one like myself goes through; but for me, no more, I have licked them.

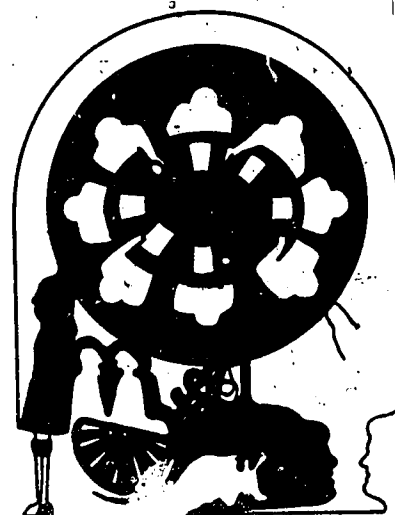
The frustrations are many and if I go through one of them, please do not think that I am feeling sorry for myself. I am not looking for your sympathy. I just want to point out a few experiences that a fellow like myself went through in life. What do you think it would be like to sit at the sidelines of a football game, basketball game, hockey game, or a baseball game, and you see your friends playing and you realize the next hour you are going out there and do a beautiful job. However, you know way back in your mind that this thing will never happen. How do you think one feels when he meets his friends on a Saturday night at the local gas station and gradually all of them disappear. They did not realize that while they were going out with girls, I would be walking home at 9:00 on Saturday night. Believe me I have done it many, many times. And I never went in the house, because my mother used to know what was happening, and I would just sit in the yard in the dark and say, well, some day. How do you think it feels to see guys go by in a car with their girls next to them, the radio full blast in the summer with the top of their car down? And you know that you can drive and they (the Registry of Motor Vehicles) forbid you to have a driver's license. But that doesn't bother me now because you see I have a license. It took me 10 years to get it but I got it. And now I drive 8 ton trucks, as well as a new \$20,000 bulldozer which I will be operating in a couple of weeks.

What I'm trying to say is, if I can do it, why can't the next handicapped person do it? Why can't they be given the chance? Why can't people stop looking on the negative side and start looking at the positive? Because that's all it takes. Believe me, that's all it takes. If we are given a chance, we can do wonders. Do you think that all the handicapped are great? No way.

Just like any other group, there are some that take advantage of their situation. They get on welfare or say, "I don't have to work; I can get public assistance." But these poor souls do not know what they are missing. In the morning I wake up at 5:00 and take our dog for a walk, come back and have breakfast, kiss my wife goodbye and then 7 men are waiting for me in the field to give them directions and orders. But I want you to know that I work right beside all of my men; shovel and pick, picking up boulders, whatever we do I am right there because I had a chance. And now I am an advocate instead of client.

Advocacy, you know, is a very difficult subject because you see, you must know how to advocate. Everything that you advocate for is different. And, the only way that you are going to beat this rotten system that we live in is to work with it and prove that it is rotten. Never, never be afraid to call a spade a spade. People that tend to hold back do not know how much damage they are doing, not only to the people that they are serving but to themselves. If you do not like your job, get out. The space is very, very valuable.

There is much, much more that I want to say, but I think I will just summarize a little bit. First of all, on behalf of all of the handicapped persons in this country, I would like to take this opportunity to thank you. You see, I took the right to be free and I took the right to be me. Second, I want to leave you with a little thought. If one fails to plan, one plans to fail.



Planning and Evaluation

The intent of this chapter is to describe two major planning problems facing a Council on Developmental Disabilities. The first problem involves the strategies a Council could utilize in undertaking its planning responsibility. A potential solution to the problem is offered in the form of a planning model. The model is intended only as an example since many Councils have already established procedures which work well for them. For such Councils, the planning model will probably prove only of passing interest. The second problem involves the relationship of DD Council and the person or persons employed to assist in the Council's planning efforts and the implications that relationship holds for the implementation of Council plans. The goal of the paper, then, is to describe one model of Council planning and to depict concerns that those assisting in the Council's planning may have.

COUNCIL PLANNING: TWO TRENDS

For the purpose of this paper, planning is defined as engaging in a process of determining which alternative solution to a defined need is most appropriate in light of given resources and constraints. Once the solution is agreed upon, planning is also required to delineate a strategy for implementing the solution. Determining the

procedures that will be used in agreeing upon solutions and implementation strategies also requires planning, and different methods are frequently used in the planning process.

Currently, two distinct planning trends exist among DD Councils. One trend is that the Council is a responding body. The Council reacts to ideas and issues generated by others. Sometimes the Council relies heavily on its planning staff as the prime source of ideas and issues. The purpose of the Council becomes one of approving, modifying or rejecting ideas.

A second trend is that the Council is action oriented, but not to the point of rejecting ideas and issues brought to it. Rather, the action orientation causes the Council to define a role for itself and its agents relevant to some problem which the Council as a whole has determined is of importance to DD persons. For example, the Council continues to review state plans or fill gaps in services, but the Council also plans activities for its members and staff which will make a direct contribution to fulfilling the needs of the developmentally disabled citizen.

Of course, action planning by a DD Council is the issue of primary concern. In order to engage in it, staff and members must accept several assumptions. The very existence of a Council is based on the assumption that persons with differing interests and backgrounds are an appropriate population to develop and review plans for DD persons. Additionally, Council members and staff must accept their own legitimacy to engage in the active planning process. The federal legislation grants this legitimacy to a degree, and some states have expanded it by legislating additional statutes. Also, Council members and staff have to assume that a member was placed on the Council, because he or she has knowledge relevant to the function of the Council. Many Council members, in fact, possess extensive knowledge about the needs of DD persons and the demographics of their state. They also represent the knowledge of others regarding what needs to be done for DD persons.

As such the Council represents an evolving organization of people constantly increasing their knowledge and experience in the needs for services for the developmentally disabled. This aggregation of people and resources represents a decision group which has both the knowledge to assist DD persons in accessing needed services and the accountability for the nature and success of those services.

COUNCIL PLANNING: A MODEL

One thing that a Council engaging in action planning learns quickly is that there are too many needs to which the Council could respond. Moreover, different members of the Council place different value on the varying needs.

The initial action for a Council, then, is the establishment of some consensus about its beliefs and priorities. There are numerous means by which this can be accomplished, but in order to be effective, a strategy seems best which allows maximum participation of all Council members and which does not allow domination by verbally fluent members. Without such a process, the decisions made may be accepted by a member, but he may select not to participate in the action or may attach the ownership and responsibility to the few verbal members.

One DD Council which utilized the action planning model found its members quickly agreeing on the major beliefs of the group. These beliefs were adopted as Council priorities. The Council also defined needs of DD persons and then ranked them by order of importance. The following excerpt from documentations of their initial planning session provides examples of the Council's responses to development of policies and priorities:

Policies - Overriding priorities for DD programs

The following statements were generated by the Council in response to the question, "What characteristic should any program serving DD people have?" The intent was to establish the general philosophy of the group. "Only a sample of

policies follow:

- A. Emphasis should be placed on the individual, his rights and the responsibility of society to meet his individual needs.
- B. Services should be designed to encourage the acceptance of DD people, recognizing their uniqueness and individuality.
- C. Services should be provided in the least restrictive manner.
- D. Each individual has a right to a continuum of services which emphasizes a movement toward normalcy.

Priorities - Rank ordered problems that DD persons face in receiving services

In response to the question, "What barriers are DD people facing in receiving needed services?", the group identified 24 barriers. The purpose of this activity was to allow each Council member to voice his concerns. The 24 barriers established by the group were then categorized into the 14 items. From the list of 14 barriers the Council was able to identify 7 major problem areas. Only the top two priorities follow:

- 1. Individuals who have responsibilities for DD citizens have a need for more information regarding developmental disabilities, service roles, services available, and their own responsibilities.
- 2. Services to DD people are being inhibited by the need on the part of decision makers, such as the DD Council, regional boards and state agencies to know who is being served, who needs to be served and what the quality of services are.

The product of defining beliefs and priorities also has several secondary effects. It provides information to non-members of the Council as to the purpose and emphasis of the Council. Of course, the taking of a stance by the Council may lead people to disagree with it and to

seek actively to alter the beliefs of the Council. Nevertheless, it may also encourage some to seek assistance from the Council, or it may reinforce the beliefs of others and cause them to respond in a positive manner to some need. Finally, defined priorities can provide a focus for planning specific advocacy activities, either regionally or statewide.

Once a Council has defined that which is important to it, it can begin to establish directions for its actions. A generally accepted method for describing what the Council will do is the development by the Council of goals and objectives. Goals indicate the long range intent of the Council. Several objectives are usually developed and associated with each goal. Objectives specify what results will be obtained over a period of time, and the assumption is made that arriving at those results will eventually lead to obtaining the goal.

For example, the Council which developed the policies and priorities previously cited also developed goals and objectives for each of their top two priorities. In this case, the Council selected to divide into two small groups and to develop the goals and objectives based on policies and priorities of the full Council. The results of their effort, which follow, were presented to the full Council for its approval:

Goal 1 - The DD Council will develop a procedure or procedures to assess the information need of those persons responsible for providing services to DD persons and to communicate information and establish exchanges in areas which will reduce information gaps.

Objective 1 The DD Council will develop a request for Proposals (RFP) to contract for the design of a needs assessment process. The RFP will designate information to be collected, viewpoints to be assessed, needs and suggestions to be identified, the population to be sampled and the product to be developed. The RFP for the needs assessment will be developed in one month, contracted in an additional month and conducted in a period of 6 months.

Objective 2 - The DD Council will stimulate the development of printed material, video materials, state television program commercial time, inservice training formats and resource bureaus, etc. to meet the information needs identified.

Goal 2 - The DD Council will form a task force of DD Council members, state agency personnel, technical experts in evaluation and other interested parties as needed, to specify the quantity and quality of information desired by the Council for more objective decision making in its program planning.

Objective 1 - The DD Council, by March 1, 1975, will develop a procedure for the continuous evaluation and review of regional board plans. The procedures will be derived from and responsive to the need for information as expressed by DD Council members.

Objective 2 - The DD Council will commission a study to review the evaluation procedure which can be used by local DD service programs and the State DD Council to assess the gaps in services and the impact that DD services are having on DD clients. The commission will contain representatives of the DD Council, regional boards, evaluation professionals and relevant others and will be charged with review of alternative evaluation strategies and resources which might be brought to bear on the problem. The end result of the study will be a report to the Council recommending a plan of Council action.

The development of goals and objectives by the Council also sets into play two other parallel and on-going activities. First, the Council must review the action goals and objectives in light of plans and resources being generated by other state public and private agencies. The process of review might entail the formal analysis of activities of relevant others, or it may entail informal discussion and review with others. Second, the Council should put into play some set of

activities to validate the worthiness of their goals and objectives. A goal could be set to have blind people learn to make brooms, and an objective would specify that they will make 50 brooms a week. But the goals and objectives could be irrelevant to the needs of blind people. To avoid engaging in misdirected activity, the Council must engage in directed inquiry to determine the feasibility and significance of its actions.

When the Council has established goals and objectives, tasks can be specified for meeting the objectives. Some tasks might be undertaken by council members and staff, while others might be assumed by state agency personnel. One method of task completion used by many councils has been the awarding of special planning or demonstration grants.

The results of Council plans can be monitored over time if the Council has clearly defined its goals and objectives. Moreover, if the actions of the Council have been well documented a major portion of the Federal/State plan can be quickly assembled.

Planning for Council action, then, is one trend in planning styles for Developmental Disabilities Councils. It requires that a Council periodically review the position and direction of its activities and reaffirm its beliefs, policies, goals and objectives. It also requires that the Council have someone to be a full-time advocate for its positions. In general, the task of carrying out the Council's plan or of monitoring others in the fulfillment of those plans has been the responsibility of a staff planner or planners. The position of planner for a DD Council is a unique one in State government, and the following section of the paper attempts to relate one of the problems that a Council must recognize that its staff faces in the role of implementing Council plans.

THE COUNCIL PLANNER

This section of the paper describes the major types of relationships and some of the consequences of these relationships for the staff planner of a DD Council. Specifically, the following types of relationships are

described: 1) the relationships between the planner and the DD Council; 2) the relationship between the planner and the state agency by whom the planner is salaried; and 3) the relationship between the planner and other external organizations, e.g. the federal agency. The relationships described do not refer to any particular state agency, Council or planner.

The DD Planner occupies a position which is essentially located between two organizations, the state agency (or agencies) and the DD Council. A person in this position usually has the responsibility of representing each organization to the other and the responsibility of representing certain aspects of both organizations to other audiences. On the one hand, the planner is seen as a member of the Council with the responsibility of facilitating internal administrative matters and representing the Council to the state agency (or agencies) in such a way that the Council can conduct its affairs as it thinks best. On the other hand, the planner is seen as a member of the state agency with the responsibility of seeing that the general expectations of the agency are not violated by the Council. In addition, the planner is expected to represent the agency and the DD Council to external organizations, such as federal funding agencies.

The administration of internal matters of a DD Council contains some issues that are not found in many other organizations. The Council members are more oriented toward advocacy and assuring the delivery of services than toward creating orderly administrative systems. Differences and disagreements between and among Council members are likely to be of an issue nature and settled by debate, group meeting or simply isolation from the source of the difference or disagreement. The infrequency of Council meetings and the specification of action by the Council require extensive time for development. This orientation does not lend itself either to "day-to-day" or urgent organizational decisions.

The relationship between the state agency(ies) and the DD Council presents a different set of conditions for the DD planner. Since he represents both organizations under differing conditions, neither organization is

certain of his primary reference or loyalty. If he is extremely successful in having the Council's expectations met by the state agency, then the agency is likely to grow suspicious. If he is seen as over zealous in presenting the agency's expectations, then the Council is likely to question his allegiances.

It is also necessary for the planner to represent the agency(ies) and the DD Council to external organizations. The essential problems here are that more of the representation must be mediated through the organization being represented. For example, if the state agency is being represented, the planner usually must "go through" the state agency. The process of "going through" has many forms. One form, for example, is the procedure of approving a report. Few people can resist changing a document placed on their desk for approval, and it does not take many "changes" before the deadline for the report is not met, and the planner has not represented the agency or Council appropriately. Another form of "going through" is when the reports to external agencies prepared by the planner are presented by someone in the state agency or on the Council. It is an unusual person who can present and interpret a report without intimate knowledge of its preparation. Given a poor representation, it is even more unusual to find someone who thinks it was his presentation of the report which was the reason for the poor presentation.

The representation of the agency and the Council to external organizations is additionally complicated by the contacts the agency and the Council members have with external organizations. For example, it will be an embarrassed planner who attempts to provide program accountability data for a grant without knowing that an addendum, written as a memo three months after the grant was approved, significantly changed the nature of the grant.

The planner, then, is in a position of having to represent an organization - the DD Council which resists management and regulation - to other state and national organizations - organizations which want systematic information about the intentions and actions of the Council but who both encourage and reinforce the discretion,

interactions and complexity of the Council.

CONCLUSION

Developmental Disabilities Councils are an uniquely qualified body to plan and advocate for meeting the needs of DD persons. Some Councils have chosen to be assertive in their planning. For those Councils, a planning procedure is necessary to assure that the views of all members are an integral part of any plans developed. Good planning can lead to significant actions by the Council on behalf of DD persons and also to the fulfillment of the legal obligations of the Council in concert with its action role. The implementation of plans requires the support of personnel who have been involved in the planning process and who understand the Council's belief and policies. Given the nature of the DD legislation, support personnel must be employees of an ongoing state agency, a policy which places individuals who assume those roles in an unique position -- one which must be understood by the Council and accounted for in Council planning. The successful Council which engages in action planning will actively include all members of the Council and staff in the planning process, and the resulting plans will represent significant tasks which are consistent with the role of the Council and the organizational competency of the staff.



Consumerism

The Developmental Disabilities Act of 1970 clearly recognized the important role of the consumer. By requiring that at least one-third of the membership of Developmental Disabilities Councils be consumers, it provided the Council with a very important resource. In addition, of course, it provided the consumers with opportunities to take an active role in planning for the development of comprehensive services for developmentally disabled citizens. The roles of consumers in advice giving, planning and advocating have been, and are being, recognized as important functions.

What has been neglected are the functions of service giving and service monitoring in which consumers can also play an important, if not indispensable, part. In a few places across the country, these functions have been recognized and field tested with very promising results. Hopefully, these results will be replicated and improved upon elsewhere.

There are several substantial reasons for involving consumers and consumer representatives, namely parents, in service delivery systems for the developmentally disabled. To identify a few: (1) parents know their own children best and this knowledge can be used to good advantage by others working with the children;

(2) often parents spend more time with their children than do others, and this time can be used to work with their children in a manner consistent with the center's goals; (3) parents can be of significant help to one another in that they share similar problems and can identify with and support one another; (4) parents can provide the program staff with ongoing evaluative feedback which can assist the program in being accountable and in making programmatic decisions; (5) parents can provide child behavioral data that can be used to monitor intervention effectiveness; (6) parents supply a source of manpower not readily available from other sources because of the lack of finances and training.

Each of these points is worth elaborating upon and most of them have been explored by other authors (Ora & Reisinger, 1971). Clearly, there are not sufficient services for handicapped children. Even though services have increased rapidly since the Bureau of Education for the Handicapped and the Developmental Disabilities Act came into being, at the rate services are expanding it will be decades before all the developmentally disabled are provided with comprehensive services. There are many reasons for this state of affairs; two principal reasons are a lack of financial resources to provide programs for the developmentally disabled children and a lack of trained personnel. To accelerate the provision of services, programs are needed which provide quality services for developmentally disabled children at low costs and do not rely completely on professionally trained practitioners for all or even a majority of the intervention services. For example, programs currently being funded by the Handicapped Children's Early Education Program are averaging over \$3000 per child served and a ratio of fewer than six children served for the equivalent of each full-time professionally trained staff member. While these costs, in terms of money and manpower, are not too great for a society to spend to assist handicapped children, at present our society is not willing to make these kinds of resources available to serve all developmentally disabled children. Therefore, professionally trained persons who have the responsibility for providing services for all developmentally disabled children must develop and implement service systems

which are likely to provide quality services with substantially lower financial and human resources.

Parents are one source of such human resources. They are readily available. They are already engaged in preparing and teaching their children and are eager to learn more effective ways to rear their children and prepare them to live in society.

OVERVIEW

A project that recognized the value of this human resource early in its inception is the Regional Intervention Program (RIP) of Nashville, Tennessee. This program was one of the first group of projects funded by the Bureau for the Education of the Handicapped under the Handicapped Children's Early Education Program in 1969.

The description of RIP is here presented both as information and encouragement to those interested in developing programs utilizing effective, low-cost consumer participation. While admittedly detailed, the description allows the Council member to examine the steps through which the service delivery system was developed and clearly demonstrates the integral part that can be played by consumers in maintaining such a system. Hopefully, it will suggest some viable answers to specific questions of how a similar program might be implemented.

The Regional Intervention Program was described by its first director as "a social experiment in which an agency of people, the Tennessee Department of Mental Health, in cooperation with Peabody College and the Nashville Junior League, provides the citizens of the state with a permanent organizational structure, with support for that structure, and with continuity of information within that structure, but the citizens themselves implement the organization to provide services to their children to their own satisfaction." (Ora, 1972)

The program serves developmentally disabled and behaviorally disordered preschool children from birth to age five from a twenty-six county mental health catchment area. Children and their families are referred to RIP by

mental health centers, pediatricians, general practitioners, public health nurses, welfare workers, parents and other agents and agencies when the family is no longer able to cope with the behavior and learning problems of the child. The time between contact with the project and the beginning of service to the family ranges in most cases from twenty minutes to forty-eight hours. Thus, RIP is a flexible service system always ready to admit additional families on a no-reject basis. If the family feels it can profit from the services of the program, it is always admitted.

The decision to become this flexible has meant that RIP had to design a system for delivering services that is capable of readily providing for new families at any time. Although RIP was originally designed to provide service through the vehicle of professionals, the utilization of parents in the service delivery system soon became a matter of necessity and desirability. A consumer-implemented service system gradually evolved wherein consumers provide all direct service and monitoring of the program, with the support provided by five professionally trained special educators. Designed and implemented as such, it is possible for the project staff (made up of parents and professionals) to provide comprehensive services for approximately fifty additional families during each year of operation. Comprehensive services include transportation, intake, parent training, individual tutoring, preschool classrooms, day care for siblings, medical and behavioral consultation, home visits, liaison with the social service agencies, placement and follow-along. Through these services, RIP's one objective is to prepare the family and the child for the child's maintenance and developmental progress outside of institutional care. This goal is realized if the child continues to make progress after being placed in a regular day care program or public school classroom.

In order to meet this objective and deliver services, RIP is organizationally divided into functional modules which achieve management objectives (Figure I). Each module is supervised by a resource person who has had professional training, but all the services are provided by parents who have been served by RIP. The entire

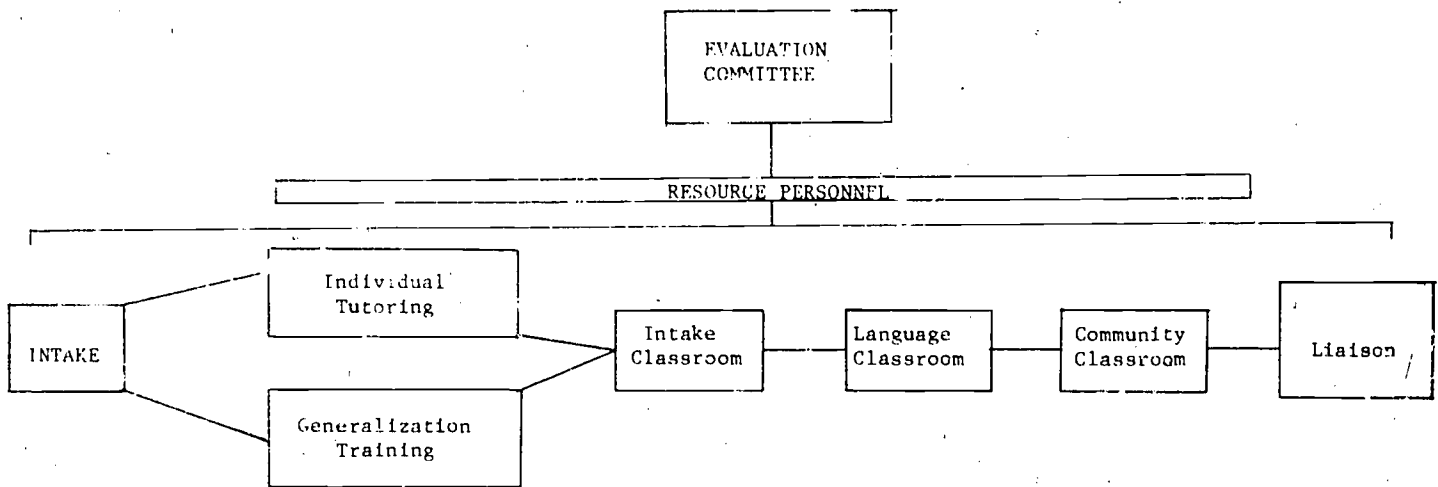
project is monitored and evaluated by an Evaluation Committee consisting of three parents and three consultants who are selected by the parents through procedures established by the Committee or parents. This committee meets regularly and has the responsibility for approving and generating project policies and for evaluating ongoing activities. All project personnel meet with the committee at least monthly to report on module activities and individual family progress.

The committee in turn transmits a monthly report, consisting of the minutes of its meeting and its comments on the meeting, to the Coordinator, Preschool Programs Branch, Division of Children and Youth Services, Department of Mental Health. The Coordinator's office has already perceived that such a system permits extremely close and politically astute monitoring with minimum administrative overhead.

The second level of the program is the professional resource staff which provides a middle-management function within the project. Each staff member in this level has specified areas of responsibility which are outlined by management objectives following the format of Reddin's Effective Management by Objectives (1971). For example, the principal of RIP is responsible for the overall administrative operations of the program. The professional staff personnel do not provide conventional special education services themselves. They work individually with parents and children only for the purposes of modeling and training, but most direct services are provided by trained parents with whom these resource personnel continuously consult, train, monitor, evaluate, and direct. Essentially, the professional staff members are consultants, providing expertise and personal support for planning and teaching, to parents who are responsible for the implementation of the program.

The third level of the program is delivery of services which is totally parent-implemented. At this level are parents who have received training to work with their own children and have demonstrated particular expertise in at least two domains: technical and interpersonal competence. Their technical competence is, of course,

FIGURE I
REGIONAL INTERVENTION PROGRAM
STAFF PATTERN



ANCILLARY
SERVICES

Transportation
Day Care
Theory Classes
Home Visits
Media Productions

constantly growing and may be in one or more areas of project services such as intake interviews, child assessment, classroom teaching, individual tutoring, home visits and child management. In every case, however, these consumers have demonstrated that they can operate within a management-by-objectives framework and can reliably utilize the data collection procedures of RIP. For at the center of all RIP services is the importance of objectives and data-based evaluation.

Individual factors such as personality style, interpersonal skills and interests are also considered in determining what responsibilities and functions the parent is to have. These decisions are made by the parents who have provided the new grant with services along with the resource personnel.

Demands for a variety of regional treatment services, constantly shifting referral patterns, and multiple funding sources over the past five years have largely determined the numbers and kinds of clients served by the RIP program. The following description of the current program in terms of its clients and referral base will, hopefully, be a useful reference to those interested in the evolution of the Regional Intervention Program.

Between June of 1969 and March 21, 1974, RIP served a total of 254 families. At present, approximately forty families are actively enrolled in the program with an approximate average rate of attendance of 65 percent. Thus, about twenty-six families daily participate in the program. These families have an average of 1.6 preschool children who attend RIP, bringing the program's daily attendance to approximately twenty-six adults and forty children.

The average RIP child is forty-one months old upon referral and generally will remain in the program for 8.1 months.

For the past five years, most of the referrals (76 to 80 percent) were males and approximately one-half of RIP's current referrals could be classified as seriously developmentally delayed. That is, significant delay

exists in the language, motoric and cognitive areas. The remainder of the children are nondevelopmentally delayed, severely behaviorally disordered children who typically have been referred as "brats", oppositional or hyperactive children.

Currently, 24 percent of RIP's families are black, having been typically referred by local Welfare Department social workers, public health department nurses, child development clinics and, occasionally, a private pediatrician.

In the first two years of operations RIP relied very heavily on local pediatricians from the Metropolitan Nashville area for referrals (in 1970-71, 76 percent of all of RIP's referrals originated from pediatricians). However, over the past three years, the pediatric referral rate has stabilized between 25 percent and 29 percent as more mental health centers, social service organizations and hospital-affiliated diagnostic clinics begin to refer to the program. Thus, the program is now fairly representative of the general population of the middle Tennessee area with 38 percent of its families in an income range below \$7,000, 51 percent between \$7,000 and \$13,000, and 11 percent above \$13,000 annual income. Further, as awareness of the program has grown, more families from rural middle Tennessee are daily attending RIP. At present, nearly 25 percent of the program's families travel more than fifty miles per day (round trip) for services and some of these commute over one hundred miles per day.

INTAKE

When parents and visitors first arrive at the Regional Intervention Program, they are shown a slide show which gives an overview of the services and philosophy of the program.

The purpose of the Intake Module is to familiarize new families with the program, to provide them with support and understanding, to determine the next steps in providing help for the family, and to invite the parents to join if they wish. The intake process is designed to

be as informal, informative and supportive as possible. Because prescriptive diagnosis and assessment is seen as an ongoing process and an integral part of service itself, there is no need to collect involved diagnostic data. Instead, the parent is asked simply to describe what the child does or does not do that is excessively disturbing. This information is then used to place the family in the correct service module and to identify parents who have had similar problems and can be of help.

Following the intake interview, the parents are shown a slide show describing the program services and are then taken on a tour of the program. It is explained that parents are expected to devote from six to nine hours a week at the program working with their children. However, once a prescriptive program has been designed and implemented for them and their child is making steady progress, they are expected to commit themselves to an additional six months of volunteer work with the project helping others like themselves.

From talking to parents who are involved in the program, they discover that most enjoy working after their child's intensive training needs are met. To most parents, the opportunity to develop talents and abilities they may not even have known they had provides an outlet for self-expression and creates a sense of satisfaction and accomplishment. Also, many of the parents have realized that the program's objectives of helping people to help their children and each other reflect their own values and beliefs. Only after the parents have had a chance to acquire all the information they need does the family make a decision whether or not to participate in the program. As soon as they join, usually within an hour or so of arriving, case responsibility passes from the Intake Module to a Training Module. The coordinator, who directs the Training Module, immediately assigns other parents who are successfully dealing with similar problems to provide support to the new family until they begin to make friends on their own. A training schedule which usually begins the next day is set up for the child. If the family has other needs, the Training Module coordinator alerts support modules. In consultation with the resource personnel the Intake coordinator can immediately

activate a massive effort from teams of trained workers as well as educational, medical and social services. By the end of the morning, the family has a list showing who to call for what and what to do next. More important, they realize that they are no longer alone. People like themselves whom they can trust are using a carefully designed system to help them.

DIRECT SERVICES

The family and child are then placed in a Service Module, either the Individual Tutoring or Generalization Training Module and a Classroom Module. The first two modules are designed to develop individual programs providing group learning experiences for the child and group teaching experiences for the parents.

A child unable to communicate appropriately is assigned first to the Individual Tutoring Module. The Individual Tutoring Module's goals are to produce functional speech or other adaptive behavior in the child and to instruct the parents about how to develop these skills in their own child at home. Training begins at the child's present level of development. For instance, it may start with getting him to look at people, to follow instructions, to imitate motions, sounds or words, or to recognize and name things.

In Individual Tutoring rooms the child's mother begins by learning to record which stimuli are presented to the child and how many correct responses he or she makes. Within a few daily sessions the parent becomes the teacher as well as the pupil. The parent presents the training stimuli to the child and reinforces correct responses, teaches the child at home every day and records the child's responses on a data sheet. All program training is designed solely to teach the parents what to do at home. The parent comes in daily to the Individual Tutoring Module to demonstrate progress made in the home program and to confer with the case manager on procedures as determined by the parent's and the child's needs. Individual tutoring experiences such as imitation and speech training are used because they have been repeatedly found to be an effective method of teaching parents. Once

skilled in these procedures, most parents can, after a little demonstration, not only teach skills like toiletting and dressing, but abide very well by the program's rule for generalization of learning: "Any desirable behavior that the child learns anywhere is thereafter required and reinforced everywhere."

Some families who enter the program do not go into the Individual Tutoring Module because they have other kinds of problems. The Generalization Training Module is designed to take care of these problems. They seek help because their child has brought them near collapse with severe tantrums, constant crying, whining, and general unmanageability. The child may have upset meals, refused to go to bed, abused himself, his parents, his brothers and sisters, and his pets, destroyed things in the home, or defied all attempts by his parents to discipline him.

Assigned to the Generalization Training Module, these families soon learn that the problem does not reside solely in the child. Research has shown that such behavior disorders in toddlers are acute and interactive and unless help is given at an early age, such children are in for serious problems.

In this module, training for parents and child takes place during a twenty-minute structured play session, which is designed to elicit bad behavior from the child. The parent is instructed to request the child to change toys every two minutes. The parent-child interaction is analyzed by continuous data recording. With the case manager, the parent follows a manual of instructions and videotapes which teaches the parents how to assume increasing responsibility for operating the module. As in all the training modules, procedures are primarily designed to teach the parents what to do at home.

In most cases the parent's request for the child to change toys every two minutes results in a considerable amount of oppositional behavior including screaming, throwing objects, sulking, and general unmanageability. Parents often respond to this behavior with almost

constant attention as they try to get the child to conform, thus, inadvertently reinforcing the inappropriate behaviors. After baselines on the parent and child behavior are established, parents are taught to ignore inappropriate behaviors and praise and reinforce appropriate behavior. These procedures normally result in significant increase in praise from the parent and sharp decreases in oppositional behavior from the child. Within a three to four week period most parents are taught new and successful child management skills.

While the family is being served in one of these modules they are also assigned to a classroom. Both parent and child begin in the Intake Preschool. In addition, if the family has other preschool children who do not have day care, they are included in the classroom programs.

The Intake Preschool does not have responsibility for the family; responsibility always rests with only one module at a time. Nonetheless, the Intake Preschool is a major training center for both parent and child. Again, a standard training manual is used by the mothers. When the parent has demonstrated that he or she can accurately record a number of dimensions of teacher and child behavior in group situations, the parent and child advance from the Intake Preschool. Continuous data recording shows when the child's behavior is acceptable for one of three other preschools. One preschool is for tiny tots, and for toddlers who function at the same level. The curriculum is built around developing gross and fine motor skills and single words. Another preschool is language-oriented and these children are usually involved in individual tutoring. However, some brothers and sisters or children from the generalization training module are included as language models. The Language Preschool works very closely with the Individual Tutoring Module. Unlike any of the other modules related to group activities, the Language Preschool sometimes assumes responsibility for a family, especially when the primary objective is to provide extensive language stimulation so that the child can enter a classroom in the community.

The third preschool is a class designed to be like

those the children will encounter in the community. Teacher-pupil ratios are lower here than in other pre-schools, and social experiences are stressed. As in all the Program's preschools, however, the child is still on an individualized course of instruction; however, he receives less individual attention than in the other pre-schools. The child's progress is evaluated on a day-to-day basis by recording behavior and comparing it with instructional objectives. The resulting information is monitored by the child's parents, by the teachers and the resource personnel, and by the personnel of the Liaison Module, who at this point, take over responsibility for the family. As the child proves to be ready for return to community schools, the issue of an appropriate match between family and community services arises. The Liaison personnel already have records on the child from the Program's own community preschool, and maintain an empirically evaluated listing of placements appropriate for various children. They investigate possible placements and consult with the parents about the most appropriate placement. When the child moves on to another primary educational system, the Liaison personnel (who are a group of parents who help as they are needed) provide support and consultation to the new teacher. They may actively assist a teacher in programming for a child placed in her class.

Also, should the family encounter further difficulties, the Liaison personnel are the link to the support or intervention systems needed. All the families going back to community services know they can obtain help from the program if they have problems. Conversely, the program does not hesitate to call on its evergrowing network of parents throughout the region for temporary assistance.

PARENT TRAINING-RECAPITULATION

In RIP, parent training and project services are the same; the entire project is designed to help parents help themselves and other parents. Parents are first taught to collect data systematically, using baseline and multiple baseline recording procedures, for the purpose of tutoring their child and evaluating the child's

progress in the preschool classrooms. Next, parents are taught the essential skills of behavior modification, reinforcement, timing, shaping, fading, stimulus selection, and programming. As they demonstrate their behavior competencies they begin to receive instruction in the general theories of behaviorism as presented by Skinner (1953) and Bijou & Baer (1961). They then learn more about child development, primarily focusing on language development, but also upon social and motor development.

Once their child is making steady progress and parents have demonstrated competency in some of the basic skills, they begin to offer volunteer services which can be the beginning of a new career for some. If the parent has demonstrated mastery in individual tutoring or generalization training, he or she can begin as an assistant in these modules. If they showed interests in one of the preschool classrooms, they could begin an assistantship there. In some cases, the parents teach others to collect basic behavioral data, but if they show programming and decision-making competencies they can take on more and more responsibilities in one of the service modules.

In most cases parents finish their six months of volunteer service and leave the service-giving aspects of the program. Some, however, stay on with the program as volunteer assistants, or in some cases where particular skills and interests are shown, as paid employees responsible for a service module (e.g., Intake Preschool). In some few cases, having demonstrated a good grasp of all functions of RIP, they would take on greater responsibilities such as directing the Intake or Liaison modules or being responsible for parent coordination and assignment. In a few select cases, some of these parents would become members of the Evaluation Committee, or would, with the additional professional training, become full-time resource personnel. Within the program all parents learn important and valuable competencies which they have an opportunity to use continuously in positions of their own choice.

EVALUATION

There are three types of evaluation performed by the RIP staff: individual child progress evaluation, group or

odule evaluation, and project evaluation. Data is considered the basis for all decision making in the program. The success of programmatic intervention is dependent upon valid and reliable data. Therefore, RIP places substantial emphasis on training staff and parents in data-collection procedures that have been designed to measure relevant behavior with reliability.

Individual data is collected in individual tutoring, generalization training, the classrooms, and by the Liaison Module. Using baseline and multiple baseline procedures, the staff observes specific behavior in various response classes such as imitations, verbal behaviors, motor behaviors, cooperativeness, attending, etc. The data are used to determine the functional effects of the intervention being employed.

Group data is collected primarily by the classroom module. In the Intake Classroom data is collected to determine both individual and group performance on the on-task/off-task dimension. The goal for each child is to be on task 85 percent of the time or more for three consecutive days. During specified times children and tasks are observed by two independent observers. These observers sweep the room at specified time intervals and independently record who is on task or off task as well as teacher attention. Percentages of on- and off-task behavior are developed after twenty minutes of classroom observation. These data are used to determine individual child progress as well as group performance as a measure of program effectiveness.

Similar data procedures are used to measure verbal behavior to determine the amount of social play and interaction in the community classroom and in the language classroom where the goals are to increase overall expressive behavior. Here, the objective is for each child to engage in cooperative play behavior at least 40 percent of the time during a free play period. The Liaison Module uses similar procedures to follow-up on children as they are placed in other settings and also to describe and evaluate other preschool programs for the purpose of cataloging potential placement settings for RIP children.

RIP is also constantly in the process of utilizing

data to determine overall program effectiveness. The Evaluation Committee regularly evaluates module performance and program effectiveness. In addition, RIP has been the subject of two major evaluations. One was conducted by the research cooperative and funded by the Bureau of Education for the Handicapped. The result of this study was the designation of the Regional Intervention Program as one of 12 exemplary programs for children with behavioral problems in the nation (General Learning Corporation, 1972). Another study was conducted, at the request of RIP staff and on a subcontract basis, in order to determine RIP's cost effectiveness as a service program (UT Industrial Engineering Economic Analysis)

Annual operational costs for the Regional Intervention Program (including all overhead, maintenance, and non-clinical services) are as follows:

Fiscal Year	1969-70	\$ 29,000
	1970-71	\$ 94,000
	1971-72	\$152,000
	1972-73	\$177,000
	1973-74	\$210,000 (projected)

Data computed on April 1, 1974, indicated that the current cost for the past five years has been \$2,291.33 per family (total direct costs divided by total families served). Data projected from the first three quarters of operation for Fiscal Year 1973-74 suggest that the cost per case during the current year will be \$2,233.63 (total direct costs divided by the number of families signed into the program in 1973-74 plus families continuing in daily treatment who signed into program prior to 1973-74).

These costs per child may seem rather high, but one must consider that the cost covers comprehensive services to the family. These services are provided five days a week for a period averaging over eight months and include parent training, transportation, day care for the child and other preschool siblings, and ancillary services. The ancillary services provided cost-free to the parents include medical, neurological, psychological, and social services, for which RIP pays over \$15,000 a year.

A review of the case files of RIP established that 158 children were "admitted" during this three-year period (1969-1972). Out of this total of 158 cases, 64 cases were identified as probable Cloverbottom (State institution for the retarded) candidates (i.e., with high probability, they would be admitted at Cloverbottom while a child). Furthermore, from these 64 cases, 10 cases were selected in which the evidence concerning the child's future commitment to Cloverbottom prior to his treatment at RIP, was absolutely certain. For each of these 64 cases, including the 10 highly documented cases, Dr. John Ora made projections concerning the probable date of admission and length of stay of the child in Cloverbottom or an equivalent institution both with and without the involvement of RIP in the case. The judgements provided by Dr. Ora for the 10 highly documented cases were then independently reviewed with complete agreement by an admission psychologist at Cloverbottom.

Assuming a 60-year life expectancy and an annual cost of institutionalization of \$4,000 coupled with 5 percent inflation, the present worth (1969) of the state's anticipated future cost of supporting the child, both with and without RIP was calculated. The difference between these two costs is interpreted as a benefit attributable to RIP and thus a savings to the state. Considering all money costs for the three years and only the savings associated with the 10 highly documented cases, the following benefit-cost ratios were obtained:

4.69 (4 percent)
3.13 (6 percent)
1.66 (10 percent)

In other words, at all three interest rates the state of Tennessee has saved more dollars than have been invested. In considering the above findings, it is important to note that the only benefits included represent dollar savings to the state and in no way to the families involved nor the obvious contributions that an individual makes when going through life as a participant in society rather than as a patient in a mental institution.

It is evident that, based upon some conservative

assumptions involving only a small percentage (7 percent) of the total families served between 1969-72, the RIP program returned to the State of Tennessee at least 66¢ worth of monetary benefits for each dollar expended on behalf of the program's clients (based upon a conservative annual discount rate of 10 percent). These figures, however, do not reflect some of the program's non-monetary benefits:

1. probable prevention of behavior problems in children born to mothers subsequent to the mothers' training at RIP,
2. development of trained volunteers who could prove useful to other community action programs,
3. improved manageability of children in public schools,
4. provision of a laboratory for testing novel approaches to keeping family life intact,
5. possible reduction in juvenile delinquency for children treated in RIP,
6. training in marketable skills for parents, and
7. possible additional tax revenues resulting from gainful employment of parents who may have been unable to work without RIP involvement.

In summary, the Regional Intervention Program is a service delivery system carefully designed to provide for, and implemented by, parents of developmentally disabled and behaviorally disordered children. It is a system which is managed by stated objectives and evaluated by data to serve the families' best interests. It is a service through which parents learn to help themselves and others like them at costs which are lower than custodial and institutional care.

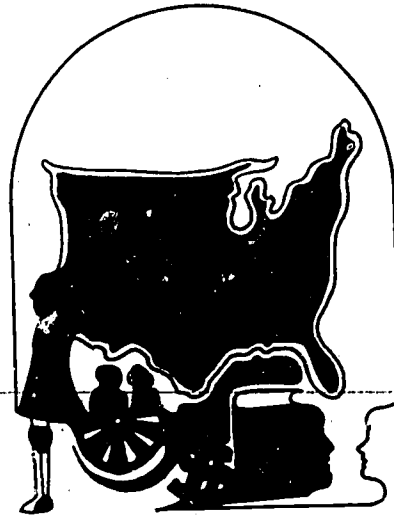
CONCLUSION

After the RIP Program was presented to the DD participants at the Winter Park Conference, a discussion led to the following conclusion: Developmental Disabilities Councils could increase consumer involvement in the planning, development and delivery and monitoring of services if they were to do any of the following:

- (1) Hold public hearings and have consumers and parents express needs
- (2) Establish hot lines for consumers to give and gain information
- (3) Hold systematically sampled interviews with consumers
- (4) Require that projects funded with DD funds involve consumers in their planning process
- (5) Require that projects funded by DD funds have consumers on their advisory boards
- (6) Require that projects funded by DD funds have ongoing monitoring by consumer committees

REFERENCES

- Bijou, S.W. & Baer, D.M. Child development I: A systematic and empirical theory, New York: Appleton-Century-Crofts, 1961.
- Final report. General Learning Corporation, BEH, 1972. Grant No. OEG-0-8-743742-5656.
- Ora, J.P. & Reisinger, J. "Preschool Intervention: Behavioral Service Delivery System" American Psychological Association, Washington, DC, September, 1971.
- Ora, J.P. "The Involvement and Training of Parent and Citizen-Workers in Early Education for the Handicapped and Their Implication: A working paper for the Council on Exceptional Children, Invisible College on Early Childhood," San Antonio, Texas, January 21, 1972.
- Ora, J.P. "Final Report for the Regional Intervention Project for Preschoolers and Parents," December 31, 1972. Grant No. OEG-0-9-520320-4535 (618).
- Reddin, W.J. Effective management by objectives. New York: McGraw Hill, 1971.
- Regional Intervention Program Slide Show. Composed, edited and reviewed by the Regional Intervention Staff from 1970-1974.
- Skinner, B.F. Science and human behavior, New York: MacMillan, 1953.
- U. T. Industrial Engineering Economic Analysis



Regionalism

This book attempts to deal philosophically, conceptually, and functionally with the Developmental Disabilities Council and its advocacy mission as an organization in state government. A very basic set of issues that underlies the operational integrity of the Council has to do with the form of the organization itself. That is, the Council must be organized in a manner that makes manifest its values and that operationally makes possible the efficient achievement of its goals.

Developmental Disabilities Councils have been committed to insuring the delivery of appropriate services to the developmentally disabled at the times those services are needed. One organizational form or practice emerging that has some potential in facilitating the Council's interest as a corporate advocate for the developmentally disabled is regionalism.

This chapter includes three sections. The first, by Humberger, presents information on regionalism as a concept and its relationship to the advocacy perspective. It includes information on recent developments in regionalism and implications of those developments for the developmental disabilities movement.

The advocacy perspective insists that, as much as

possible, the consumer's experience of services and the service delivery system should judge the efficacy of those services and systems. Much of this issue is addressed in the chapter by Fusco. The advocacy perspective also urges that, in as much as possible, services should be organized, monitored and implemented by consumers or their families. The chapter by Wiegerink, Parrish and Buhl describes an approach to consumer organized and implemented services. The major advocacy issue ~~involved is to insure more specific accountability to the~~ consumers.

The second section of the chapter, by Bauer, presents a parent's view on organizing groups and accessing services for developmentally disabled children. It is included to emphasize the personal stance that any organizing effort must have to harness services for people. Regional or local groupings have as one of their primary reasons for being to oversee and assess the value of services and have first-hand knowledge of developmentally disabled citizens.

The third section, by Davis, describes some strategies and methodology for implementing programs within the general advocacy-oriented regional perspective provided in the chapter. This section, "organizing communities", focuses on procedures for interfacing different groups, setting priorities for program design, and implementing and developing constituencies for program implementation.

SECTION I REGIONALISM AND ADVOCACY

The primary relationship being examined here is that between citizens and their needs on the one hand, and the capacity for governmental structures, on the other, to meet those needs. In particular we are concerned with the capacity for regional, multicounty structures to deliver services to developmentally disabled persons.

Regional or multicounty service delivery systems are not a new phenomenon, although during the past few years federal and state governments have increasingly

moved toward rationalizing all responsibilities into the hands of locally elected officials. More and more, the primary sponsor for such service delivery is the Councils at the county level. Councils of Governments (COGs) are similar to Economic Development Districts, Regional Planning Commissions, and similar regional agencies, in their efforts to provide increased cooperation among local officials and to facilitate planning for services on a common basis.

The significance of the regionalism issue for DD Councils arises from the fact that while COGs once had only coordination and planning functions assigned to them, and then usually in physical resources, they are now being given service delivery functions in both physical and human resource areas. The State of North Carolina, for example, has 17 COGs, and the Governor has just issued executive orders assigning "umbrella" service delivery responsibilities to them for aging, manpower, family planning, and nutrition services.

The importance of understanding regionalism is also heightened by the recent publication of several documents on Substate Regionalism by the National Advisory Commission on Intergovernmental Relations (ACIR) in Washington. In addition to a complete analysis and survey of the status of substate regionalism existing in the country now, ACIR has also suggested model legislation for states to implement what is known as the UMJO Strategy -- Umbrella Multi-Jurisdictional Organization Strategy. The differences between the present COG structure and the proposed UMJO approach to regional human services is outlined in the documents. The most significant difference in the model proposals is that UMJOs have the authority to deliver services in any given multicounty region. COGs, on the other hand, are purely voluntary organizations with no power, only planning and coordination responsibilities. Locally elected officials could secede from the COG at any time if it was not felt to be in their best interests.

The significance of this development in terms of advocacy in the Developmental Disabilities movement is that in COGs, and particularly in Economic Development

Districts, there is usually some provision for minority and low income participation in decision making, though the majority is usually comprised of locally elected officials. In the UMJO approach, no such provision is made with a minimum of 60% locally elected officials, and with no specifications as to the remaining membership. It is safe to say, given the results of the ACIR report, and given the reactions of locally elected officials to the community action programs of the last ten years, that minority and low income groups will not systematically be represented in the decision-making system. In fact, clients in general are more likely to be advocated for by others who may not know, understand, or even sympathize with their particular service needs or problems.

In sum, under the UMJO strategy, the locus of decision-making power over human service programs at the regional level is moving dramatically out of the hands of the specific service agencies and into those of local elected officials. In this writer's view, this represents an unfortunate and potentially disastrous shift in terms of self-advocacy, client input and control over decisions affecting their lives directly, and the possibilities for delivered services to directly reflect the needs of the clients. Putting structural distance between services and clients by concentrating decision-making power in the hands of those not directly affected serves neither the developmentally disabled citizens of the community, nor the community at large. It is an infringement on the democratic rights of specific client groups to have so little control over the service delivery systems which heavily impact on their lives.

Returning to the concept of regionalism, we have as a society developed problems of a magnitude that require governmental responses on a level greater than the town or county. Pollution and transportation are two excellent examples of how individual citizens' needs cross jurisdictional boundaries. Hence, over the years local governments have banded together to form special districts which have the characteristics of allowing a regional response to a problem without threatening the autonomy or power base of specific local governments. The nature of our regional problems are such, however,

that in the past ten to fifteen years there has been a vast proliferation of these special districts, most of which had no coincident boundaries. A citizen may be subject to the authority of up to 15 or 20 different legal entities, from school districts and county government to pollution abatement and sewage districts, each with different boundaries.

Seeing this proliferation as a threat to rationality in planning and cost effectiveness, the federal government sought, through specific legislation, to promote regional coordination and planning. Primarily through the housing acts of the last ten years, and particularly what is known as 701 Comprehensive Planning legislation, COGs have been encouraged; primarily metropolitan areas have been required to create coordinating agencies to qualify for funds.

As COGs and Development Districts or Planning Commissions were given increasing responsibilities, however, it became painfully clear that they were not professionally equipped to handle them. Also, local elected officials had neither the time, resources, nor in some cases the interest, to support the regional agencies. There is a distinct fear among these officials that COGs have been voluntary organizations; there has been serious questions as to their viability.

Therefore, it is reasonable to see the ACJR recommending a strategy for multi-jurisdictional organizations with significantly greater authority, particularly mandatory membership and taxing power. However, without representation of clients in the decisions which affect their lives, and with the concentration of that power in the hands of local elected officials who may or may not have the interests of low income or minority groups at heart, the legitimacy of the new UMJO approach is in question.

What of the future of these regional agencies in relation to Developmental Disabilities? The future of DD in relation to regionalization rests in an understanding of what the individual states are doing, their direction in terms of regionalizing human services or adopting the

UMJO legislation, and their ability to establish DD service regions in a stance which can take the greatest possible advantage of the UMJO movement. We stress that by making clear our own values on advocacy, and by understanding the relationship between advocacy and the regional structures we are proposing, we can then be one or two steps ahead of our states. Perhaps we will be in a position to influence and educate our state planning offices about the needs for client input into the regional decision-making processes.

The regionalization process, in conclusion, is an old one, but has the strength to overcome many of the localist obstacles presently being thrown in its way. Decentralization of service delivery is the current mode of the federal and state governments, and will continue for some time to come. We must understand what this means in terms of services for the handicapped, and, if at all possible, take the initiative to insure that our advocacy values are reflected and that the needs of handicapped people are reflected in a legitimate regional service delivery system.

SECTION 2

A PARENT'S VIEW OF THE ADVOCACY ROLE OF DEVELOPMENTAL DISABILITIES COUNCILS

To be truly effective, any organizing effort in behalf of developmentally disabled citizens must encourage and utilize input from individual consumers - from those whose involvement is direct and personal. Consumers, or their representatives have first hand knowledge of the needs of developmentally disabled clients, information which is essential if the service delivery system is to be truly responsive to real needs of people.

This section explores, from a personal perspective, ways in which parents can become effectively involved in the service delivery system. Additionally, it addresses the issue of the Council's role in insuring the provision of comprehensive services to the developmentally disabled. As planning and as advocating bodies, DD Councils are in unique positions to maximize consumer involvement. In this effort, regional mechanisms have much potential as

organizational means for coordinating community services.

One aspect of advocacy is parent education and training, and I would like to share with you some of my experiences in organizing parent groups over the last five years. Some were more successful than others, and I hope the reasons for the successes or lack of same may be helpful to you in your own programming.

The first parent group with which I was associated was school-centered and grew out of the mandatory parent education, training and therapy programs which we attended as part of the conditions for keeping our child enrolled. The school in Pittsburgh provided a day program for developmentally disabled children ages 3-6. There were no restricting qualifications for the child, such as being ambulatory and/or toilet trained, which was unusual at that time. The school served a 250 square mile area so many parents drove long distances, as did I (50 miles round trip), to get their children to school. At first the idea of making three extra trips per month for parent education, parent therapy and mothers' training sessions seemed like a burden, but attendance was required to keep one's child enrolled so we all did it. The sessions, however, were so helpful, and we all grew so much in understanding and skills through them. Soon we were talking about forming a Parent's Association to make the work of the school known to the people in the communities it served and to the legislative representatives from the area in order to promote understanding of developmentally disabled children and to encourage legislative changes in their behalf. Our achievements included major coverage in all community newspapers and an increase in the number of volunteers serving the school as a result of community awareness. All state and federal representatives from the districts served visited in the school and saw the needs of the children and what could be accomplished with training and intervention.

I believe this program, centered in the school, was successful because a close common bond between parents was developed, particularly through the education and therapy sessions. In addition, our county and state associations for retarded children were strong united

organizations, and we worked with and through them making our small voices even louder.

Two years ago we moved from Pittsburgh, Pennsylvania to Columbus, Ohio; a friend who was a caseworker for Franklin County Children's Services called to ask me to talk with a young mother of two microcephalic children who currently were placed in foster homes. The mother wanted to have her children at home with her, but expressed a need for training in how to handle them when she did have them home again. I then began to call all agencies in the county to inquire if a parent education and training program was offered that was open to parents who were not directly attached to any particular facility. A number of phone calls netted only referrals to other agencies, and finally I was referred to the very caseworker who had called me in the first place. At this point I decided that no such program was available and that the need for one existed. I then contacted the Director of the Citizen Advocacy Program in the Council for Retarded Children of Franklin County who worked with me to design a series of eight monthly evening seminars. We listed the cooperation of the Franklin County Program for the Mentally Retarded and made the sessions available to parents of children in their preschool and early childhood classes, as well as to persons in the community at large.

What were the results? Both parents and teachers in the Franklin County Program who attended the sessions found them informative and helpful. We were disappointed, however, in that we did not reach the numbers of people in the community that we knew might benefit from the program. Even providing trained baby-sitting services and transportation did not bring out the people we had hoped to reach.

After comparing our effort with other parent training programs, such as those operated by the Portage Project in Wisconsin and the Regional Intervention Program in Nashville, Tennessee, we concluded that the large group structure only works well when it is school-centered, attendance is mandatory, and parents feel a common bond (e.g., from the same neighborhood, or

children in the same class). On a countywide or regional basis alternative forms of parent education in which the service is taken to the parents through home trainers, volunteer parent visitors, behavior modification specialists, etc., seem to be more effective.

Currently we are beginning a Volunteer Visitation Program in which parents of handicapped children are being trained to work with parents of newly diagnosed developmentally delayed persons. Referrals are made to the Program Coordinator by members of the medical community who have all been alerted to the program and the services it provides. Follow-up is immediate with an attempt to match parent visitors to the family on the basis of age, type of disability, etc.

It is too early yet to evaluate the effectiveness of this program, but it is hoped that this will be a way to reach those who need information and training and to shorten their search for appropriate services, if indeed they even attempt to find them. Of course, one of the major problems facing this program (as well as others) is finding those persons who need services. Those who are already in touch with agencies or enrolled in schools and programs may need improved services, but they are at least known to the service providers. There are many other persons who have as great or greater need who are not known to the service providers, they may be unaware of existing services or may lack the time, money or emotional stamina to pursue them. And there are still those who would rather hide their problem than seek help for them.

A large number of the persons who are not reached are in inner-city, rural, or poverty areas. These are the same areas wherein a large number of persons are born or become developmentally disabled through circumstances such as poor nutrition, inadequate pre- and postnatal care, inadequate housing, or lead poisoning. If we are to reduce mental retardation (for one) by half by the turn of the century, it will be necessary to reach out to these areas and to take comprehensive services to all the people without waiting for them to come seeking them.

In my view, the Developmental Disabilities Councils have a responsibility to encourage and provide this kind of outreach either through their regional organizations or through some similar structure. The Developmental Disabilities Councils are in a position to have an overview of services provided and should set as a priority item the attempt to close the gaps between services and to eliminate the overlaps. I do not suggest that the Councils try to do the entire job themselves or that they have to create a new level of bureaucracy, but rather that they serve to coordinate the efforts of those agencies which are already functioning and encourage them to broaden or limit their programs where necessary and to cooperate with other agencies which are similarly involved.

I would also suggest that the Developmental Disabilities Councils not limit themselves to working with agencies which specifically serve developmentally disabled persons, but that they work with and through all community-centered programs (e.g., settlement houses, neighborhood recreation centers, community mental health agencies and 4-H, etc.). It is through these other groups not solely concerned with developmental disabilities, that the "missing person" (those who need services but may not have sought or found them) will be located.

Generally, there will be a need for legal, educational and citizen advocacy programs, but the extent of each will vary from one community to another. The following are questions that the Councils might ask themselves in the course of establishing a comprehensive advocacy program:

What is the number of people needing services?

How will they be located?

What are the needs of the constituents?

How will those needs be determined?

What is the best way to provide services?

Will the Council coordinate all advocacy efforts

of other agencies?

How will agencies report to the DD Council?

What control will the DD Council have over the efforts of other agencies? (e.g., the quality and scope of programs.)

How will this control be effected?

Who will keep a check on the system? How?

Will there be separate offices for Citizen and Legal Advocacy or will all advocacy efforts be coordinated by the same person or committee?

I would hope that the Developmental Disabilities Councils would organize themselves in a way that would allow them to serve as a bridge between various agency advocacy programs so that information is shared, gaps closed and overlaps eliminated. A DD Council, informed as to the number of developmentally disabled persons, their needs and those of their families, and aware of the scope and quality of existing services, is in a good position to take the initiative in guaranteeing the rights of developmentally disabled persons as their advocate before the leaders of state government.

SECTION 3 ORGANIZING COMMUNITIES TO SERVE DEVELOPMENTALLY DISABLED CITIZENS.

This section focuses on a general organizational strategy for both forming and interfacing groups in order to implement programs. A procedure for organizing groups and interfacing them is presented as a tool for program implementation and insurance that programs are developed from an advocacy perspective. Two points relevant to an advocacy approach are emphasized here: (1) that groups, in this case regional councils, take the initiative in pursuing programs they consider important as opposed to assuming a more passive, responsive stance; and (2) that programs and priorities are always set from the perspective of developmentally disabled citizens.

Since many constituencies are required in order to provide comprehensive, coordinated programs, existing groups must be identified, and those persons who are not presently organized must be brought together. Such groups can include direct service providers, administrators of service organizations, consumer organizations, and developmentally disabled citizens. In order to bring together these different types of groups, and those groups to be formed, an additional, neutral group is needed that can coalesce these different segments. The term "neutral" is used deliberately to imply that no one constituency dominates or controls program direction. To insure an advocacy perspective, the neutral group must always view and initiate its program development from the perspective of disabled citizens.

Disabled citizens are often viewed as incompetent or unable to be self-determining. Disabled citizens are considered an essential component of the design put forward here. This stance is a value judgment based upon two points: (1) developmentally disabled citizens should have access to services that meet their particular needs, and (2) a choice of services should be available since that choice provides checks and balances on quality and increases the dignity of the individual.

Several principles are cited to capture some of the above statements.

In the area of service program development, regional areas suffer from problems of lack of coordination of existing services.

Practically speaking, any effort for the development of services begins with some individual or group, within or outside the community, who perceives the need for such services.

No one individual or group, within or outside the community, represents the spectrum of services needed in toto.

Although third party support or active participation in a planning effort can provide expertise

otherwise not available, ownership of the proposed program must be maintained in the hands of the community itself.

If the third party, a neutral group, is seen as a facilitator and information source, it must recognize the need for freedom to negotiate with different factions in the community in order to form a coalition of support.

Agencies which financially support planning efforts frequently put limitations on the constituency of the planning group and/or activities of that group.

A service program planning effort, which will ultimately belong to a given community, should be carried out by a team which includes representatives of the following key factions: service providers, service receivers, community decision makers, general public, and third party facilitators or neutral groups.

Considering the goal of designing a service program for developmentally disabled citizens, we must assume that there exist several groups within each area who have resources which could benefit and identifiable needs which could limit such a program. Those resources and those needs must be identified in a nonthreatening manner. The first step is to formulate an information base.

The role of the neutral group is designed to stimulate and facilitate the development of programs, and to follow up on program implementation. In addition, the neutral group would serve as a vehicle for communication between existing service agencies, the decision makers, the public, and disabled citizens during both the planning and implementation phases. Serving as a communication link, the neutral group becomes the principal source of information, thus maintaining a powerful independent integrity.

The following principles can be formulated in

establishing an information base:

- 1) An essential prerequisite for any organizational program development effort is the existence of an information base related to the identification of existing resources, the identification of existing needs and the compilation of issues of concern to all individuals and groups identified.
- 2) The indigenous neutral group should be the prime contact, "own" the information base, serve as a vehicle for communication between the factions in the community, and lead in the implementation of programs.

Once the information base is collected, central program needs can be identified. This process narrows the number of persons and groups to be involved in the design and implementation of programs. Usually included are parents of disabled citizens, disabled citizens themselves, service providers, administrators of service agencies, and leaders of relevant organizations. Groups to be involved need to be contacted individually, because each will have a different perspective of the issues. To combine groups indiscriminately when there is differential information on issues is to: (1) artificially associate persons unaccustomed to working together on an issue, (2) confuse the issues by aggregating a variety of perspectives, and (3) emphasize points of discrepancy and dissension rather than points of agreement.

We have adapted a procedure entitled "Nominal Group Procedure" (Van de Ven and Delbecq, 1971), which is a tool that facilitates the setting of priorities and using those priorities as a base for combining information across groups to develop programs.

NOMINAL GROUP PROCEDURE

This procedure assumes that there are statements more pertinent for some groups than for others. For example, it is a more appropriate question to ask health providers "What are the barriers you face in delivering health services?" than to ask the question "What are the problems families face in gaining access to health services?" The latter question might be more pertinent to families than the former question.

An outline of the procedure follows:

1. With groups of five to eight participants, hand out an 8 x 11 sheet of paper with a clear statement of the issue (often specified in terms of barriers) pertinent to that particular group, typed on the top of the sheet.
2. Request each person to individually make a list of responses to the issue typed on the sheet of paper. Request no talking. Let the participants know that their lists will be shared with each other.
3. The recorder (person conducting the procedure) lists on a flip chart each person's list of responses, one item at a time per person, round-robin until all items from everyone's list are exhausted. Allow duplication, avoid discussion, justifications, etc. Number each item (1...n).
4. The recorder reads each item for clarification and understanding. Items should not be eliminated. Duplications may be grouped (for example items 3 and 8 may be grouped and treated as one item).
5. The recorder hands out five 3 x 5 cards to each participant. Have each person select and write, by name and number, one item per card, the five most important items. Once those five are chosen, give the most important item of those five a "5" and circle that number; the next most important item receives a "4" and so on down to the least important item which receives a "1".
6. The recorder prepares a tally sheet on the flip chart as follows:

PRIORITIES

Item #	Ranks assigned to them	Sum of Ranks	Weighted Sum	Priority
2	2, 1	3	6	3
14	3, 4, 1	8	24	2
7, 20	5, 5, 4	14	42	1
18	2	2	2	4

7. The recorder asks for the items (column 1) and their ranks (column 2) from each participant, round-robin, one item at a time, starting with the most important item, that item receiving a rank of "5", and so on until each participant's list of five is exhausted.

8. The recorder sums the ranks (column 3), multiplies that sum by the number of persons giving that item a rank (column 4), and the highest weighted sum is the top priority, the next highest sum the second, etc. (column 5). Example numbers are provided in the above table.

Several principles are cited that should be considered in using any procedure that interfaces groups:

- 1) Rather than assembling all interested parties or groups in order to determine priorities for program development, it is recommended that the information base be broadened to include the priorities of each faction independently.
- 2) The Nominal Group Procedure is a useful tool for identifying group priorities. It emphasizes consensus rather than dissension and clarifies issues of concern for each group.
- 3) Coalitions can be formed on the basis of priorities of the individual factions, once again emphasizing points of similarity.
- 4) Such coalitions perceive group ownership of the problem and can thus work as a group to plan solutions.
- 5) Individual group members of the coalition, feeling less threatened, are more willing to pursue the task of implementation and to contribute the resources available in their own particular group. Implementor roles thus become defined through the process itself.

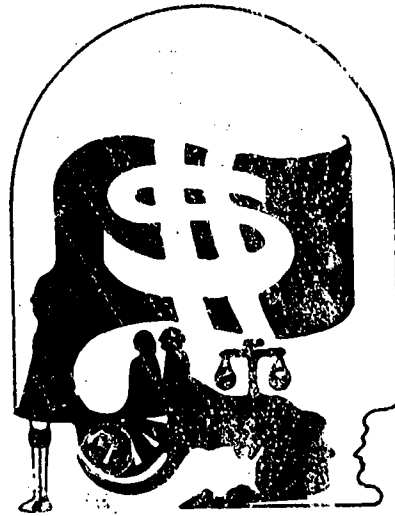
The title of this section, "Organizing Communities to Serve Developmentally Disabled Citizens", and much of the content presented, might suggest to the reader that everyone's involvement in the development of services is being advocated. This point deserves clarification. The neutral group involves all possible interested individuals and groups in initial information interviews. The members of the neutral group and planning coalition, however, are selected on the basis of their role definition related to the central theme of concern derived from those interviews -- not everyone should be involved in the actual planning and implementation effort.

The task of information gathering has an essential by-product. Constituencies are developed which cut across

interest group boundaries and which focus on the new programs being developed. Representatives from each group have unique information to contribute (for example, parents are the only experts available on the problems their particular families face). The interfacing of these groups through an information base has the effect of developing a unified constituency without dissention and confrontation. The different groups then have a basis from which to jointly develop programs since each has a defined and contributing role.

Our experience suggests that, while considerable effort needs to be spent on understanding the existing social network through the process of sequenced information sharing information develops role definitions for each group and allows the cooperative development of new programs. Checks and balances emerge because the commitments become accountable to one another, and they cooperatively defend the program to outside groups and develop resources both with their coalition and with outside groups.

Note: Delbecq, A.L. and Van de Ven, A.H. "A Group Process Model for Problem Identification and Program Planning." Journal of Applied Behavioral Science. Vol. 7, No. 4, 1971, 466-492.



Revenue Sharing

"The true measure of a society can be seen in what it does for its members who are least endowed." 1961
John F. Kennedy

Traditionally, the American public has relied on a competitive society instead of a rights entitlement society. Historically, we have resorted to Social Darwinism in law, in government, and in distributing public resources. We have a track record for allocating public resources - including human services - on a winner take all and profit-oriented basis. The losers have included groups at a competitive and profit-return disadvantage: the poor, the disabled, the very old, and the very young - as well as those denied the opportunity to compete - racial minority groups and women. As losers, these groups have received unequal treatment and an unequal share of public services such as education, health care, housing, employment, protection, and legal aid. A competitive system of distributing resources puts the burden on the individual to access his share.

On a small scale, the Vocational Rehabilitation program - the oldest federal program for the handicapped (enacted 1921) epitomizes the competitive, profit-

oriented model for service delivery. Eligible clients, often referred to as the "cream of the crop", are those who demonstrate potential for gainful employment in the competitive market. Rehab has justified the investment of public funds on services for handicapped people by the profit-return - that is, rehabilitation programs produce tax paying citizens. Until the Rehabilitation Act of 1973, service priorities have been directed to the client with the highest potential - not the one with the greatest needs. Severely and multiply handicapped people, like the developmentally disabled, have been excluded from the programs especially "targeted" for the handicapped, such as V. R., as well as from generic human services available to nonhandicapped individuals.

Much recent discussion in the Developmental Disabilities field focuses on two complementary, often overlapping, strategies for changing this situation: resource development - the accessing of people, information, materials and money; and advocacy - the securing of rights and entitlements for vulnerable individuals and groups. Both are change-oriented and both share the common tactics of monitoring, intervening, and influencing.

Those who seek a share of public resources in behalf of the developmentally disabled, monitor, intervene, and influence the decision points of public resource distribution at policy, administrative, and disbursement levels. Actions being taken include: lobbying the state legislature and the U.S. Congress, engaging in grantmanship and purchase of service contracting; developing community organization and support, exercising policy review and channelling planning input to all state-federal plans for human services; reviewing and participating in local and state budget decisions; developing coalition support, and identifying and developing key local and state agency contacts.

Advocacy activities for the developmentally disabled range from the one-to-one fellowship or friend services programs, to referral and follow along services, to representation at administrative appeals procedures related to service eligibility determinations, to

litigation for individuals or groups (class action suits), to the evaluation of service providers and monitoring service standards compliance. The advocate's focus is on the decision points of service delivery at the policy level, the administrative level and at the "hands on" program level.

Opportunities for collaborative strategizing between the resource accessors and the advocates are limitless. For instance, the local developmental disabilities advocate is in a key position to monitor publicly funded community services and require accountability from public agencies. The consumer advocates provide an essential information link and feedback to lobbyist and community organizers on the implementation of public policies and operation of public programs; similarly, class action victories in right to service litigation require resources for implementation and will require legislation, appropriations, and community support. In this second case, resource development provides follow through for advocacy.

The challenge for Developmental Disabilities Councils, and indeed for all of us in the Developmental Disabilities movement, is to synchronize our activities in resource development and advocacy to deal with changing patterns of public funding represented in new programs such as Revenue Sharing and the Supplemental Security Income program.

As DD Councils dedicate their activities to change, using resource development, advocacy, and other strategies, they engage in what I affectionately refer to as the legitimate hustle - that is, inducing, shoving, pushing, jostling, and hurrying the system to yield funds and services and opportunities for the developmentally disabled. This chapter explores past and future trends in federal funding of human services and attempts to identify some appropriate organizational response to the legitimate hustle as it is manifested under New Federalism today.

PAST AND FUTURE TRENDS IN FUNDING AND ORGANIZATIONAL RESPONSE

The 60's

During the 60's, social action and social legislation opened up a plethora of new federal programs for many disadvantaged groups, including the mentally retarded. The War on Poverty, Vista, rural and urban poverty programs, neighborhood health centers, and many other programs targeted special needy populations. By this action, the federal government deviated from the traditional competitive mode and asserted a responsibility to protect the rights and entitlements of vulnerable groups and to direct the flow of public resources to target groups previously underserved by local, state, and federal governments.

Major federal initiatives of the 60's to distribute services and resources to disadvantaged groups can be characterized by:

- 1) The Funding Mechanism: Federally supervised grant programs
- 2) Two guiding principles for social change:
 - a. Use of advocacy services to inform people of their rights and provide expert assistance and legal procedures in obtaining services.
 - b. Enforcement and mobilization of consumer participation and rights in planning and implementing services.

These policies have influenced public funding trends in 1974. It is important for Developmental Disability advocates to analyze the "good ol' days" for strengths and weaknesses, and the short and long range implications for today and tomorrow. What worked and what didn't work to deliver services on the basis of human rights and entitlements?

The Categorical Grant

The 60's categorical grant programs channelled Federal funds to specialized services for defined target groups. Money to plan, construct, and staff special programs flowed from the federal treasury to service organizations often by-passing state and local governments. Typically, categorical grants impose conditions on local recipients including "matching", contributing a portion of the total expenditures.

Decision making and accountability rested in the Nation's Capital - in the Congress and in the executive departments. A handful of effective advocates, like Elizabeth Boggs and Elsie Helsel, could and did make significant impact on legislation and appropriations for the disabled at the national level. The mental retardation legislation of 1963, 1965, and the creation of the Bureau for Education of the Handicapped provided specially targeted programs. Developmental Disabilities professionals and their agencies learned to participate in grantsmanship, a variation on the legitimate hustle theme. Service providers knew who and where to call in HEW for information about funding. From the point of view of resource development and service providers, the system was safe and controllable.

The security of the days of categorical funding beckons to many of us who look back nostalgically to the 60's as a time of vigorous federal enforcement of the rights of individuals to special services. Accustomed, albeit conditioned, to pulling the categorical lever to access federal funds, we felt safe. And many of us grew comfortable with our ability to hustle that system.

Without question, the categorical programs of the 60's made important first steps towards equal entitlement to public services for many people who had been denied services in the past. The Migrant and Seasonal Farm Workers Assistance Programs, the Older Americans Act, a cluster of Appalachian development efforts, and the Neighborhood Youth Corps - all legislative accomplishments of the 60's - demonstrated a commitment of our national government to a more balanced share of public resources

for all citizens. Some daring program innovations were funded, service intervention theories were tested, and successful approaches to human service problems were documented. And that is significant.

Yet, it is important to remember that, while government protection of categorical groups' services shielded many individuals previously at risk in competing for services, the competition for grants among professionals, universities, and voluntary agencies came to an all time high. Providers developed the skills of grantsmanship RFP's, grant writing, budget fudging, and referencing the Catalogue of Federal Domestic Assistance. And for better or worse, the prospect of federal dollars lured volunteers, parents' groups, and universities into the business of providing direct services.

Most importantly, the categorical approach has not achieved an equitable distribution of federally supported services to individuals in need. Some crucial inadequacies of the "categories" include: gaps in eligibility - many needy people, for instance, the working poor - don't "fit" target group definitions; gaps in services and lack of coordination among fragmented services - or "Does Special Education talk to Social Services?" - probably not; creation of specialized services for target groups only, segregating the eligible individuals from non-target (i.e. non-handicapped community).

Advocacy and Consumer Rights

However, it is not the mechanism for distribution of public funds that will really distinguish the 60's. What set the last decade apart from others was the deliberate federal action to redistribute political power and influence to disadvantaged groups, particularly the blacks and the urban poor, and to challenge the traditional service institutions at the local level. Authors Alan Gartner and Frank Riessman note: (Barr)

Where there is a strong tendency to reject, simplistically, the sixties for their failures, for the expectations raised but unrealized, it is important to maintain perspective and to recognize

that the source of the many powerful cultural and institutional changes that are creeping into our lives actively began to appear in that era of protest. (Gartner & Riessman, 1974, p. 9)

These new relationships were to a large degree accomplished by two subtle strategies: advocacy services and consumer organizations and participation. Direct federal efforts were of course most dramatic in the area of the poverty programs and civil rights. Sargent Shriver, former Director of the War on Poverty, described the Economic Opportunity Act as "for the poor what the National Labor Relations Act was for unions. . . . It establishes a new relationship and new grievance procedure between the poor and the rest of society." (Piven & Cloward, 1971). Administered by a new agency, the Office of Economic Opportunity, (OEO), programs under this legislation performed a variety of advocacy functions for the poor. The issue was welfare rights.

Staffers in federally funded storefront neighborhood service centers took sides with the poor and became skilled in fighting local welfare departments. Lawyers joined the social workers, challenging and reversing welfare decisions:

A series of judicial decisions in the 1960's has the effect of undermining some of the regulations by which the relief rolls had been kept down. For decades reformers had lobbied unsuccessfully for legislative repeal of residence laws, man-in-the-house rules and employable mother rules. But in the 1960's, these foundation blocks of the "poor law" were washed away by one court decision after another. (Piven & Cloward, 1971).

Between 1966 and 1968, OEO spent \$85 million on legal services. OEO attorneys, in 250 projects, promoted "institutional change through lay reform." Test cases and class action suits were litigated. Significant victories were achieved in public welfare law. In many instances, the mere threat of court action by legal advocates prompted welfare departments to make procedural

changes and release information and manuals.

Paralegals, nonprofessional personnel trained in specific facets of welfare law, served as "lay advocates." In 1964, one of the first training programs for paralegals was established by OEO at the Dixwell Legal Rights Association in New Haven.

Advocates broke through an official information barrier by forcing welfare agencies to release procedural policy statements and welfare manuals previously unavailable. Handbooks, pamphlets, fliers, and welfare guides alerted the poor and their advocates to the ins and outs of service benefits.

By 1968, neighborhood service centers employed 100,000 professionals and community residents - a formidable corps of outreach workers. Their efforts helped forge an informed constituency among the poor. Welfare recipients learned about their rights and entitlements to service and the specifics of welfare policy. Most important, the poor learned that people could fight welfare departments successfully. In the decade ending Dec. 1970, the welfare caseload increased by 225%. (Piven & Cloward, 1971).

Corollary to their advocacy enterprise, the Federal government advanced a policy of "consumer participation." The involvement of the consumers (in this case the poor themselves) was of course a major principle of 60's social programs. The OEO law required maximum feasible participation of the poor in planning and implementing programs, giving them what Robert Kennedy called "a real voice in their institutions."

One of the most significant power resources the government provided was a principle that the poor should be involved in policy making, in programs that affect them. (Piven & Cloward, 1971, p. 274)

What the Great Society did was begin to come to grips with the sources of this resistance by exerting various forms of pressure . . . on local government for the reform of its service systems -

a point that critics constantly overlook.
(Piven & Cloward, 1971, p. 268)

The war on poverty programs, numerous community boards, and, indeed, the Developmental Disabilities Act of 1970 - with its consumer oriented State Planning Council are examples of legislated involvement for special groups of consumers. The consumer movement took hold with the general public also. In 1960, no state had a consumer affairs office; by 1970, thirty-three did; by 1973, all fifty states, 110 cities, and 25 counties had such offices. Federal consumer protection laws and consumer information and education programs have facilitated consumer entry to the decision process in the public and private sectors. Many public interest groups have used consumer participation to gain leverage in decision making. Authors Gartner and Riessman (1974) also note that with the involvement of consumers, the real advocacy issues of quality, equity, appropriateness, and accountability in human services have surfaced and must be dealt with by agencies and professionals:

With the 1960's came demands about the quality of these (human) services and controls by the consumer regarding their character and directive. This is an extremely important demand, one that goes right to the teeth of the battle for human services . . . the demands of the 1960's for consumer involvement, greater participation, and the general expansion of service awareness are critical elements in the battle [for human services]. (p. 65)

1975 - New Federalism

This review brings us to our present predicament - that is, coping with a new philosophy and style in Washington - The New Federalism. It is not our purpose to discuss the pros and cons of political theory here. It is important that we focus on the real life impact of the New Federalism and on what we must do to adjust to some new rules of the hustling game. The New Federalism is changing basic and familiar organizational relationships among Federal, State, and local levels of government.

New Federalist policies aim at decreasing federal discretion, influence, and regulation of publicly funded programs. The funding mechanisms we have grown so comfortable with are being replaced by two major innovations - "cash out" and revenue sharing. We are already feeling the impact of these two funding devices and can expect their impact to dominate federal support of human services for a good many years to come.

Cash Out

Cash out changes the form of federal benefits. Federal money payments would be made to individuals instead of funding for direct services; the federal government would provide cash assistance to eligible, needy individuals. Many services now provided would be replaced, "cashed out", either through increased money, payment, and cash grants to individuals or through intermediate strategies such as vouchers, negative income taxes, and insurance. Individuals would then be free to buy their own services. Proponents of this approach cite the following advantages: individual choice, simplified administration, and the efficiency of the private economy market incentives.

Revenue Sharing

By this mechanism, the federal government makes block grants to states and local governments in broad areas (health, education, social services). States and local cities are free to decide priorities and programs and allocate funds with little federal regulatory control. General revenue sharing and special revenue sharing for housing, manpower, and Social Services are now operating. A revenue sharing bill for health is pending in Congress.

Both of these new funding strategies are consistent with the move toward "decentralization": that is, shifting responsibility for social programs away from Washington to state and local officials, to individuals, and to the private sector providers. Such a shift, of course, has a multiplier as well as a geographical or spatial effect. We have multiplied the decision points.

38,000 units of local government are deciding how to spend \$30 billion in general revenue sharing; by 1976, 1400 district offices of the Social Security Administration will be determining eligibility for SSI benefits of nearly 9 million individuals; 50 states and thousands of local prime sponsors are allocating more than \$3 billion in special revenue sharing for housing and manpower in FY 1976.

While such decentralization results in a much needed simplification of administration and accounting from the federal perspective, it increases the complexity of the decision and allocation procedure as viewed by the individual.

What happens to vulnerable individuals - the disabled - who have multiple service needs over a long period of time? How do the disabled hustle this system? How do they see to it that local government is responsive, that is, allocates funds to provide for their human service needs? How do they know when their eligibility for benefits is wrongfully denied because of misinterpretation of SSI policy at the SSA district office?

These are not only questions of responsiveness in allocating public resources but also questions of accountability. Who is monitoring the 38,000 units of local government to see what happens to \$30 billion - not the Department of Treasury. And SSA's quality assurance procedures for SSI are incapable of checking the appropriateness of "informal denials" of SSI applications.

In both programs, there are too many decision points, with yes/no authority over public resources, to monitor efficiently from a centralized base. Our recent experiences with SSI and revenue sharing indicate that in the absence of some external accountability, disabled people benefit poorly from these public programs. A few illustrations:

A General Accounting office (GAO) report, based on a survey of 250 local governments including the 50 cities and counties that received the large amounts of

revenue sharing funds in 1972, reveals that programs for vulnerable groups with high service needs received little from general revenue sharing. The study prompted Rep. John Brademas (D-Ind.) (1974) to say recently that local units of government are "almost totally ignoring handicapped persons, children, and the elderly in the use of revenue sharing funds."

Of the local revenue sharing budgets surveyed by GAO:

- 1) Only about 3/10 of one percent, or \$4.3 million of the \$1.374 billion available to the governments surveyed, went to programs for the handicapped.
- 2) Only 18 governments surveyed spent any of their revenue sharing money on programs for the handicapped.
- 3) Only about one percent or \$15.4 million went for children's programs.
- 4) Only 2/10 of one percent or \$2.9 million of the total entitlements were directed to programs benefiting the elderly.

It is clear that revenue sharing dollars won't flow into human services or developmental disability programs without action at the local level.

Oversight hearings on SSI by the Senate Select Committee on Aging documented that thousands of needy disabled applying for SSI benefits have been experiencing 7 and 8 month delays in processing their forms. Rigid policies operate on the "law of deterrence" principle. Outreach programs to enroll newly eligible disabled children and adults in SSI are nonexistent. Disabled individuals experience a total lack of proper program linkages from SSI to emergency assistance, Medicaid, food stamps, social services, and sometimes vocational rehabilitation. Many disabled individuals have been denied their legal right to:

- 1) file a written application for SSI (one million individuals were denied a written application in the first 3 months of the program)

- 2) request a presumptive disability determination
- 3) receive \$100 emergency payment
- 4) receive manual "force payments" each month after they have waited 30 days or longer for an eligibility ruling

In January 1975, syndicated economics journalist, Sylvia Porter, wrote that the program (SSI) "is not the great reform law it was heralded to be. It is a disgrace." The SSI program requires eligible individuals to assert and prove a claim to benefits. It is an adversary procedure, not a helping service. The program and the administrative machinery are not designed to seek out and deliver needed benefits. These service statistics illustrate the point:

Millions of eligible individuals are not receiving benefits.

*SSA, conservatively, estimates 7 million individuals are eligible for SSI payment.

After 12 months of the program, 3.8 million people are receiving checks.

*SSA estimates that one million needy disabled children are eligible for payments. In Dec. 1974, fewer than 68,000 children were receiving benefits.

Needy disabled people wait months for benefits.

*Processing time for disability applicants under SSI ranges from 2 to 8 months.

Basically, the decentralized funding mechanisms pose two problems for the disabled and their advocates:

- 1) Protection of individual rights and entitlements to public benefits
- 2) The advocates right to know and question how decisions are made in allocating public funds

We need to examine the cash-out and revenue sharing

methods of resource allocation to identify what we can do, and how we can organize to see to it that this system works in a way that is open and responsive to disabled individuals.

Simulating the Advocacy - Resource Problem

In conjunction with this conference, DDTA developed a set of materials to simulate the problems a disabled individual faces in applying for benefits under the Supplemental Security Income (SSI) program. Using this approach, planners, advocates, handicapped individuals, and other DD Council members assume the roles of disabled applicant, Social Security Administration Claims Representative, Social Services Case Worker, Vocational Rehabilitation Counselor, and Legal Advocate. The materials and a description of the procedure appear in the Appendix.

In the first segment, the disabled person, Mr. Long, is allowed five minutes at each of the three service points (SSA, Social Services, and V. R.). His objective at each service point is to make an application, establish eligibility, and claim the maximum benefits package. Staff at the three service points imade the objective. However, when Mr. Long goes through these service points a second time, he is accompanied by a legal advocate who assists him in accomplishing his objective.

Summary

The resource development groups in Denver focused on three areas for DD Council advocacy in response to problems of the disabled SSI applicant. First, the group stressed the need for State Councils to develop training experiences for direct service delivery staff in SSA District offices to develop a better basic understanding of programs and resources available for the handicapped at the federal, state and local level. These staff development efforts should include content to sensitize staff to the needs of the disabled and to assist staff in their ability to communicate with handicapped people. These training efforts are seen as an essential first line effort to improve the decision

making and the "helping capability" of those who have face-to-face contacts with SSI applicants.

Second, in view of the deficiencies of the SSI program in responding to the needs of disabled applicants, DD Councils should continuously monitor the implementation of SSI, identify specific state and local problems, intervene at the policy making level to improve the program (such as persuading states to provide supplemental payments for the disabled) and act in coalition with other state DD Councils and concerned groups to influence national policy decisions, such as the Church amendment.

Third and finally, DD Councils must provide information and individual advocacy assistance for potential applicants. Councils must assure that there exists in each state rigorous outreach activities (especially to reach needy disabled children), and availability of legal and paralegal counseling to help disabled applicants through the SSI application process and the appeals process when necessary.

DISPLAY

OBJECTIVES: RESOURCES MODULE

That participants develop:

Commitment that DD Councils have an important, essential role in monitoring service agencies and intervening in behalf of the disabled.

Commitment that DD Councils have an essential role in influencing the system to accommodate and be responsive to needs of the disabled.

Understanding of monitoring and influencing tasks, resources, and strategies as related to public assistance and revenue sharing.

Enhanced communication skills, interviewing, presenting.

Enhanced analysis skills of primary source documents - Law, Regulations, Guidelines.

SSI SIMULATION PROCEDURE

In this simulation, five individuals play the following roles:

Disabled person	Mr. Long
Social Security Administration Staff	Mr. Cartell
Social Services Case Worker	Mr. Comfort
Vocational Rehabilitation	Mr. Wittington
Legal Aid	Mr. Hart
A sixth person acts as time keeper and facilitator	(Hammer)

Participants are urged to use role descriptions provided in the simulation. There are two reasons for this:

- (a) The plot can develop. Some role descriptions contain errors in policy interpretation. These staff errors are common SSI pitfalls throughout the country, and we will want to illustrate these for discussion later.
- (b) The participants can relax. No participant need feel that the role play is a test or quiz of his knowledge of the SSI program. Participants need not feel personally responsible for SSI program content or details; participants need only follow the role as described.

This simulation takes about 30 - 35 minutes and can roughly be divided into three segments. Participants should have 10 - 15 minutes in advance of role play to review their materials.

I. First Segment (15 min.)

Disabled Person (Mr. Long) has 5 minutes at each of the three service points.

- Social Security Administration (5 min.)
- Social Services (5 min.)
- Vocational Rehabilitation (5 min.)

His aim at each office is to:

- Make application
- Establish eligibility
- Obtain the maximum benefit package

Because of rules, regulations, attitudes, and mistakes designed in the service point roles, Mr. Long doesn't accomplish much.

II. Second Segment (5 min.)

Mr. Long goes to Mr. Hart (Legal Aid) to request help in accessing services. Mr. Long briefly reviews his experience to date. Mr. Hart and Mr. Long set some basic goals and objectives, i.e. make written application for SSI, request "flagging" for presumptive disability.

III. Third Segment (15 min.)

Mr. Long, accompanied by the advocate well-versed in the SSI rules and procedures, goes through the three service points. As before they have 5 minutes at each point to:

- Make application
- Establish eligibility
- Obtain the maximum benefit package

IV. Debriefing

Following the role play, participants need 5 - 10 minutes to "unload" their roles, feelings, reactions. Facilitator should help individuals feel comfortable about their performances by helping to show some positive aspect of each player.

V. Discussion

The group steps back from the individual situation to develop a list of generalized SSI issues. Usually participants have some prior contact or experience with SSI and its problems. These experiences will generally reinforce problems programmed into the situation, and, may in fact bring up new problems.

Discussion issues are listed in outline attached.

Materials

3 desks, 3 chairs for SSA, S.S., V.R.

Signs legible for group indicating:
Social Security Administration
Social Services
Vocational Rehabilitation

Wheelchair for disabled person*

Chair for legal aid

SSA Regulations, Manual, Forms, Public Information
Pamphlets, V. R. Regulations

*Optional

DISCUSSION ISSUES:
SSI SIMULATION

The simulation design programs these issues into the role play. Others may also emerge.

District Office

Application

--Importance of written application

--Means Test
common misinterpretations

--Substantial Gainful Activity
troublesome policies

Presumptive Disability - An Expediting Procedure

--"Observable"

--"Flagged" for DDU

Referral to Other Agencies

--Lack of Mechanisms

--Lack of Criteria

Social Services

Eligibility of SSI Applicants

Mandatory Services

Designing the

Optional Services

State Service
Package

Federal Cuts in Social Services - \$2.5 Billion
Ceiling

Medicaid Eligibility for SSI Recipients

Vocational Rehabilitation

Referral by DDU

Basic State Program

--Who is accepted for service?

--Who is eligible for service?

Priorities for Serving Severely Disabled

--New V.R. Regulations

Key Definitions

--"Employability"

--"Productive Activity"

Legal Aid

The Appeals Processes

--SSI

--Social Services

--Vocational Rehabilitation

Legal Aid Programs as a Resource

Use of "Paralegals"

Resources for Training Paralegal Advocates

Resources for Funding Programs of Legal
Advocacy

Rusty Long, Developmentally Disabled

Personal Information:

Age: 25 years

Developmental Disability: multiply-handicapped athetoid cerebral palsied individual; limited mobility; confined to wheelchair; speech impediment

IQ: 129

Work Activity: sheltered workshop program @ \$35/month

Residence: living with parents

Parents Income: \$30,000

Personal Resources: \$1,000 in trust, inheritance from Aunt Tillie

Personal History: participated and excelled in model special education program; evaluated at age 19 by local vocational rehabilitation agency and denied eligibility for services because lacked vocational potential.

A notice in a periodical published by and for the cerebral palsied alerted you to possible SSI benefits.

Go to the Social Security District Office to apply for SSI. Also try Social Services and Vocational Rehabilitation.

You have 5 minutes at each of the service points; Social Security, Social Services, and V. R. to:

1. apply for benefits
2. establish eligibility
3. get the maximum benefit package available

You will then meet Mr. Hart, a legal advocate, who will assist you in your efforts to establish eligibility

for services. Go to each of the service points with Mr. Hart. As before, you will have 5 minutes at each service point to:

1. make application
2. establish eligibility
3. acquire maximum benefit package

Good luck!

Mr. Cartell, SSA Claims Representative

You are a claims representative in a Social Security District Office responsible for a three county area, Joplin, Orange, and Southford. You have thirty years experience in processing claims for the Title II Workers Insurance Program under Social Security. You are now responsible for processing applications for aged, blind, and disabled people under the new Supplemental Security Income Program - an assistance or welfare program.

In processing applications for SSI, you use criteria and policy guidelines outlined in the Code of Federal Regulations, published in the Federal Register and two in-house documents issued from the Baltimore SSA Headquarters: The SSI Handbook and the Social Security Claims Manual. These materials are provided.

In addition, you apply the following understandings and interpretations to SSA policy.

I. Regarding acceptance of an application for SSI

- A. If a person comes in to apply for SSI and appears to be "clearly ineligible", and "if that person readily accepts the explanation of why he is ineligible, an informal disallowance is appropriate". (Handbook section 1420; Senior Citizens, p. 29.)
- B. Fill out an application form for a disabled person if you think he will prove to be eligible for disability assistance when:
 1. The district office finds that his income and resources meet the means test. *As a rule, you don't accept an application from a disabled adult living at home if his parent's income and resources exceed the means test.

and,

2. The Disability Determination Unit (DDU) finds

that medical records indicate a disability as prescribed in Regulations and that the individual can not engage in substantial gainful activity.

*As a rule, you don't accept an application for disability assistance from individuals who, although disabled, can perform substantial gainful activity as defined (Regs 416.931 - 416.934) to include "work activities" and employment in a "sheltered workshop." These applications would probably just be ruled ineligible by the DDU.

II. Presumptive Disability

It is within your power to rule that a disability applicant is automatically eligible to receive payments for up to 3 months while awaiting DDU disability determination. The basis for this predetermination is presumptive disability as detailed in regulations 20 CFR 416.951 to 416.954.

However, the Claims Manual limits you to readily observable disability: (Claims 12752)

1. An amputation of 2 limbs
2. An amputation of a leg at the hip
3. An allegation of total deafness

Does the applicant meet these criteria?

Applicants suffering other impairments and seeking presumptive disability must offer medical documentation which is referred to the DDU and flagged for expedited decision. (Regs 416.9536)

III. Referral

Applicants for SSI assistance are automatically eligible for some Social Services provided by the state under Title VI.

Applicants must go to the local Social Services office to claim any services.

It may be appropriate to refer some disabled applicants to Vocational Rehabilitation. This is usually done by the DBU. You have no guidelines for making such a referral.

J. D. Comfort, Social Worker

You are in a local unit of the State Social Service agency responsible for a 2 county area (Orange and Patter-son). Your agency is well known as the place to go for assistance payments and services. As of Jan. 1, 1974, basic payments for the aged, blind, and disabled were turned over to the Social Security Administration. (The program has been floundering ever since. Now maybe people will appreciate what social workers like you have been doing for years). You still provide money and services to AFDC families.

You offer the following benefits to the disabled.

1. Supplemental payment for disabled individuals, \$15/month after SSI eligibility is established.
2. Some mandatory services:
 - information and referral
 - protective services
 - services to remain in own home or return to community
 - services to meet health needs
 - self support services
 - homemaker services
 - special services for the blind
3. The optional services include:
 - foster care services
 - social group services
4. However, your state has recently received a cut in Federal funds available for Social Services and the Agency Administrator has issued an austerity policy.

5. SSI recipients are eligible for Medicaid. That is determined by the SSA District Office and it is their responsibility to inform the recipient of services.

Delmus Whittington, Counselor

You are a local Vocational Rehabilitation unit.

The V. R. program is the oldest Federal categorical program for the handicapped. Recent amendments to the V. R. law have made substantial changes. In the old days, the program helped the disabled return to the labor force and become tax paying citizens. The program really paid for itself. Under the revised law, V. R. is supposed to serve the severely disabled. Getting those folks into jobs will take a miracle - and a lot of time and money. The severely disabled may never be gainfully employed.

As a counselor, you are responsible for evaluating applicants, deciding whether to take applications, and developing an individualized, written plan for each client accepted into the program.

You have a copy of the Federal Regulations for the V. R. program with relevant definitions and requirements marked. Use these in interpreting the following instructions to evaluate Mr. or Ms. Long, a disabled applicant.

Basically, you see clients in three categories:

1. Those referred by the DDH - either Title II or Title XVI (SSI). These clients are paid for 100% by the federal government and must be expected to achieve "substantial gainful activity" e.g. \$200/month income.
2. Clients of the basic State Vocational Rehabilitation program (80.20 Federal-State funds) must have "vocational potential" in order to be accepted.
3. Clients who are severely disabled. The new Rehabilitation Act of 1973 places priority on providing V. R. services to the "severely disabled". [Regs 401.31 (b)]

Taking the Application

*The Application Decision and Eligibility Categories -
Is it likely this person may be eligible for V. R.?

I. Does Mr./Ms. Long fit #1, the 100% category? See requirements:

A. Does he/she meet requirements 401.124 (a) 1-4?

- 1) disabling impairment is not rapidly progressive.
- 2) without Rehab services this person will continue to be eligible for SSI payments.
- 3) with Rehab services the person will achieve "productive activity" *and can reasonably be expected to terminate eligibility for SSI payments.
- 4) cost of these services will be offset by non-payment of SSI benefits.

*"Productive Activity" is generally assumed to exist if the person earns \$200 or more/month.

II. Does he/she fit criteria for regular state programs? See 401.33 (b) Basic Conditions.

A. substantial handicap to employment

B. employability - Employability is defined in V. R. Regs. Sec. 401.1(g) as:

"Employability" refers to a determination that the provision of vocational rehabilitation services is likely to enable an individual to enter or retain employment consistent with his capacities and abilities in the competitive labor market; the practice of a profession; self-employment; homemaking; farm or family work (including work for which payment is in kind rather than in cash); sheltered employment; homebound employment; or other gainful work.

If Mr./Ms. Long doesn't fit category A or B perhaps this person is eligible for services as a "severely

disabled" person under category C. The regs define severely handicapped person on p. 42475, Sec. 401.1 (w).

- C. "Severely handicapped individual" means a handicapped individual:
- (1) Who has a severe physical or mental disability which seriously limits his functional capacities (mobility, communication, self-care, self-direction, work tolerance, or work skills) in terms of employability; and
 - (2) Whose vocational rehabilitation can be expected to require multiple vocational rehabilitation services over an extended period of time, and
 - (3) Who has one or more physical or mental disabilities resulting from amputation, arthritis, blindness, cancer, cerebral palsy, cystic fibrosis, deafness, heart disease, hemiplegia, hemophilia, respiratory or pulmonary dysfunction, mental retardation, mental illness, multiple sclerosis, muscular dystrophy, musculo-skeletal disorders, neurological disorders (including stroke and epilepsy), paraplegia, quadriplegia, and other spinal cord conditions, sickle cell anemia, and end-stage renal disease, or another disability or combination of disabilities determined on the basis of an evaluation of rehabilitation potential to cause comparable substantial functional limitation.

Remember, severely handicapped applicants must show "employability" in order to qualify for eligibility. (See definition of employability above.)

The Eligibility Decision: Evaluating Rehab Potential

You must make a decision about Mr./Ms. Long's eligibility for V. R. service. This decision will be based on an interview with the applicant and information provided by the applicant. Your decision about this person's eligibility or ineligibility for V. R. services is based on

your evaluation of his/her rehabilitation potential through one of three means, as appropriate:

- (a) Preliminary Diagnostic Study - basically the client history.
- (b) Thorough Diagnostic Study - client history, plus professional work-ups, observations
- (c) Extended evaluation of up to 18 months is indicated where there is a substantial handicap to employment and there is uncertainty about the person's ultimate employability - or job potential. These evaluation procedures are described in the Regs p. 42481, Sections 401.34, 401.35, and 301.36.

The Services Decision - What Benefits are Available

Services for which your agency may receive Federal reimbursement for eligible individuals include:

- Diagnosis
- Evaluation of rehab potential
- Counseling, guidance, referral
- Physical and Mental restoration services
- Vocational and other training, including books, tools, materials
- Maintenance
- Transportation
- Services to family members when necessary to the adjustment or rehabilitation of the handicapped individual
- Telecommunications, sensory and other technological aids and devices
- Placement in Employment
- Post employment services
- Occupational licenses, tools, equipment

The individualized, written rehabilitation program developed by V. R. counselor and client specifies service goals and service benefits. (For a description of individualized program, see 401.39, p. 422482, Regs.)

Mr. Rick Hart, Legal Aid Advocate

You are a legal aid service Advocate (not necessarily an attorney). You will be asked to help Rusty Long get the maximum benefits possible at each service point: SSA, Social Services, and Vocational Rehabilitation. To do this, you will have a grasp of the regulations governing each program and an understanding of the appeals process.

You will have these materials to assist you:

- *National Senior Citizens Law Center Manual
- *SSI Regs, Claims Manual, Transmittal Letters
- *SSI Forms, and list of evidence applicant must present
- *Social Services Guide
- *Vocational Rehabilitation Regs

The following rules will help you at each service point.

SSA District Office

1. Pages 122 - 131 of Senior Citizens details the Appeals Process at SSA.
2. Remember: The appeals process is open only to the individuals who file a written application. Get a written application on file for your client.
3. The district office is misinterpreting a crucial regulation re: income limits. The income and resources of parents of an adult disabled individual may not be deemed to that person even if residing with his parents.
4. Request expediting procedures on flagging for presumptive disability. You know that disability determinations are taking 4 - 8 months for SSI. Your client clearly meets disability rules so you want to speed

up the eligibility determination process.

Social Services

Aggressively inquire about Social Services stipulated under the State Plan. As an applicant for SSI, the disabled person has a right to some services even before his SSI eligibility is established.

Vocational Rehabilitation

Check the V. R. regulations for appeals procedure.
(Sec. 401.46, p. 42484 Regs)

Advocate Hints

Get name and phone number of staff contacts at each agency.

Gently explain that you will keep in touch with them weekly until the application has been processed.

Be sure to chat briefly with Long to find out where he's been, what's happened at the three points to date, and what he wants. How can you help? You want to make certain that Long is involved in decision making about his future.

REFERENCE LIST

Brademas, J., Congressional Office News Release, June 12, 1974.

Gartner, A. & Riessman, F., Service Society and the Consumer Vanguard. New York: Harper and Row, 1974.

Piven, F. F. & Cloward, R., Regulating the Poor. New York: Pantheon Books, 1971.

Raleigh News & Observer. Jan. 10, 1975.



Public Awareness

DD Councils must engage in public awareness activities in order to help make the DD Act work. Moreover, Councils must lead the way in changing attitudes and myths about citizens who are disabled. Finally, they must stimulate the development of new resources and better services for the handicapped.

As a planned communication and advocacy activity, public awareness programming encompasses a wide range of concerns. For example, it involves explaining about the Act. It involves describing that DD citizens are persons with dignity and values who have a right to be trained to their maximum and a right to live as happy and as normal a life as possible. It involves telling how citizens can be helped, what services are available, and what gaps exist in services. Ultimately, public awareness activities seek to advocate and generate concern, support, and involvement among numerous publics.

The remainder of this chapter is divided into two parts. The first deals with an introductory description of a public awareness planning and development framework, while the second part outlines resources available to help a council get their planning underway.

PLANNING AND DEVELOPMENT FRAMEWORK

Public information planning and development strategizing are crucial to DD Councils. Hopefully, the following framework will assist the reader to conceptualize an advocating awareness program which carefully examines alternatives for communicating what, to whom, for which purposes, when, how, and with what effect.

Planning Program Purposes

Because Planning and Advisory Councils want to nurture public awareness on issues related to DD, they must be able to clearly outline their program purposes or goals. To help the reader think about this planning activity, here is a list of seven purpose statements for consideration:

- 1) Stimulate the development of new laws, reforms, community services, and/or appropriations dictated by the needs of DD citizens.
- 2) Promote acceptance and understanding for developmentally disabled citizens and the DD concept.
- 3) Facilitate the development of the DD citizen's self concept, skills, and knowledge.
- 4) Provide reliable, accurate, and current information on the DD law and numerous related concerns.
- 5) Keep DD citizens or advocates informed about available services and rights so that they may participate and gain full benefits from them.
- 6) Promote activities of the DD Council and facilitate the positive development of relations between governmental, public, and private agencies.
- 7) Cultivate new publics who may act on behalf of the DD movement.

These seven information, persuasion, and motivation purpose statements are intended as examples. They should be viewed as jumping-off points for Council communicators to delineate their own purposes. After all, it is essential to know what is to be accomplished and what needs are to be satisfied.

Having accomplished this planning step, the Council can move on to the next phase.

Researching

This analysis phase calls for intensive and extensive data probing. All relevant opinions, observations, attitudes, and reactions of persons to be associated with the Council's public awareness program should be consulted. Furthermore, program needs should be clarified and verified prior to additional planning. As a consequence, it is hoped that parts of a program would be better seen in relation to the whole. Therefore, background information is vital to the next step in planning which involves the matching of their specific messages and delivery channels with their specific audiences.

Planning for Audiences

Audiences, like purposes, must be identified, analyzed, and agreed upon. Most often, the audiences which will receive the messages can be subdivided along different dimensions. For example, size can be divided into meaningful categories such as a single person, small group (up to 100), or mass (100 or more). Occupation, sex, and education are other dimensions. Finally, assumptions about an audience's knowledge base, values, feelings, and needs should be explored by Council communicators.

Many of the typical target audiences (or "publics") for a DD program include legislators, educators, doctors, attorneys, social service professionals, high school students, consumer groups, and parents. Of course, greater acceptance and understanding can be fostered among these and other publics. Apathy and avoidance can be changed. New laws and services can be stimulated. Positive

relations among agencies can be promoted. However, to accomplish these and other worthwhile ends, a close examination and understanding of the intended audiences is mandatory.

Message Planning

Having delineate purposes and audiences, a Council must cope with the complex issue of message determination and design. Precisely what advocacy content--facts, opinions, interpretations--should be prepared? Is it difficult or simple to understand? Does it ask for a response or offer rewards?

In general, DD Councils have two broad messages. The first deals with the Council, what it is doing, and its state plan. The second broad message (and probably the more important) concerns the DD concept and those citizens who are developmentally disabled. The following statements (Nelson 1973, Waldman 1973, and Paul 1974) provide the basis for both kinds of messages. They are offered in order to stimulate initial Council discussion on the issue of designing and clarifying messages:

- 1) The client, the developmentally disabled person, has constitutional rights as a citizen. Denial of any of those rights compounds the disability. Those rights must be secured including, or especially, in those instances where the disabled person is not able to rise to his own defense.
- 2) The developmentally disabled person has a right to live in his own community. If rejected by his own family, he has a right to resources for a decent life without compromising his own personal integrity.
- 3) The developmentally disabled person has a right to pursue a life beyond stigma. This requires an educated citizenry, an accommodating physical environment, alternative resources which are not characterized by demeaning labels or exclusive incompetency criteria for

participation, and an advocate to monitor his well being and assist in increasing productive and adaptive interaction between the developmentally disabled person and his environment.

- 4) The developmentally disabled person has educational, psychological and physical needs which must be met appropriately, sufficiently, and on time. The developmentally disabled have a right to appropriate educational and treatment resources. No sub-human or even sub-standard environment--physically, socially, or morally--can be rationalized as acceptable.
- 5) The care giving systems are, themselves, a source of information from which we can exact information for developing a message from the DD Council.
- 6) What can be done to prevent developmental disabilities?
- 7) What is being done to prevent developmental disabilities?
- 8) What are developmental disabilities, what are the causes, including those for which prevention is, at this time, unknown and what is the potential for a developmentally disabled person?
- 9) What special services need to be provided for developmentally disabled people, or what is this community doing to provide special services?
- 10) What are the advantages of early intervention?
- 11) How is a program for developmentally disabled people run? Feature a specific pre-school program, an educational program, or a work training program.
- 12) Use interview with employers plus state and national statistics.

- 13) Does your community offer maximum opportunities for "normalization" of handicapped people?
- 14) Citizen Advocacy: what it is, why is it needed, and who will do it?
- 15) Feature stories about local professionals, why they entered the field and what they do.
- 16) Feature stories about local developmentally disabled people.
- 17) Feature stories about members of the community and how they help developmentally disabled people:
 - a. parents
 - b. direct service volunteers
 - c. businessmen who employ the handicapped
 - d. businessmen who supply sub-contract work
 - e. volunteers who help on fund raising
 - f. people available for speakers bureaus
 - g. bureau members, Council members, and committee members
- 18) Current Council activities

Naturally, message design relies heavily on one more factor: a Council must know and understand its DD citizens.

Planning for Delivery Channels

Since much will not be written in this chapter about the intricacies of different delivery channels (e.g., film, brochure, newspapers, slidetape, special events, seminars, speakers bureau, press kits), we would like for the reader to consider a particular planning framework. It was developed by Read (1972) for matching and selecting channels with messages and audiences. While Read admits that his format is not based on a scientific formula, his intuitive guidelines may be helpful for public awareness planning:

Mass media channels. We should achieve maximum communication efficiency by using mass--media channels under the following conditions:

1. The audience for the message is large. The mass media, in fact, offer the only practical channels for reaching large, general audiences.
2. The message is simple. This does not mean that the message lacks importance, but the concept should be easy to grasp and understand.
3. The message is timely. There is need to reach audiences quickly.
4. The audience is exposed to the mass media channels. A large share of the intended audience subscribes to and reads newspapers, or listens to radio, or watches television.
5. Time and money are limited.

Group channels. The following conditions suggest the use of group channels (meetings, conferences, field days, and direct-mail services):

1. The audience is relatively small, specialized, easily identified, and highly motivated.
2. The message is either complex, highly specialized, or both.
3. Communication effectiveness depends in part upon immediate audience response and feedback. The audience does more than receive the message.
4. Message content is more important than timeliness.
5. Time and other resources are available.

Person-to-person channels. The conditions that suggest the use of person-to-person channels are almost self-evident and include the following:

1. The audience is small, and motivation may be slight.
2. The message, simple or complex, must be fitted to the individual needs of the receiver.
3. The timing of the message is not critical.
4. Time and other resources are available.

The exceptions. There are exceptions to all guidelines, of course, and we find many exceptions for

those above. (p. 303)

Planning for Evaluation

No public information plan would be complete without some consideration for evaluation. For just like other advocacy sponsored activities, the Council must collect information in order to gauge their effectiveness, as well as provide data for continual decision-making purposes.

Since Councils use many different planning and evaluation systems for gathering data about program impact, effectiveness, and objectives attainment, we cannot suggest an overall methodology for public awareness. Furthermore, the state of the evaluation art for this area is not that scientific or sophisticated. Of course, there are elaborate techniques and forecasting procedures which are being experimented with and implemented by large corporations. However, these are very expensive and usually too obtrusive for Council purposes.

Therefore, what are some methods which can be designed and used to evaluate different dimensions of a plan? The following suggested procedures could be employed to collect data for program assessment:

- 1) Clipping service--to keep track of how many newspapers are running the Council's releases and other stories.
- 2) Estimated numbers of persons reached as a result of televising a TV program.
- 3) Numbers of persons writing to the Council for information about its activities or Plan.
- 4) Names and addresses of persons responding (via a WATTS telephone number) to a radio campaign sponsored by the Council.
- 5) Evaluation forms containing satisfaction and impact questions that are collected and analyzed following a public education seminar or workshop on topics such as SSI and revenue sharing.
- 6) The frequency of messages transmitted via radio and TV.

- 7) Appearance of a new governmental ruling, community service, or appropriation attributable to a comprehensive Council program.
- 8) Data from a Speakers Bureau
- 9) Number of times bank, library, or department store asks for displays or booths.
- 10) A third party panel to assess, using predetermined criteria, the impact of face-to-face activities (e.g., One-to-One Day in Tennessee).
- 11) Circulation figures and feedback (formally solicited or informally provided) from readers of a Council newsletter.
- 12) Post card feedback data on a film or slidetape that is circulated by the Council.

Regardless of the methods developed and used, the Council should make sure that its evaluation procedures are tied closely to its program goals. Furthermore, it should document as best as possible its successes and failures. In this way, decisions about the overall plan can be more closely scrutinized, changed, and improved over a period of time.

Coordinating the Program

Ultimately, the Council must arrive at a decision regarding what needs to be said, what materials developed, for which audiences, and for what purposes. A Council may be fortunate to have the services of a full or part-time staff member to coordinate their public information planning, a talented task force or subcommittee on public information made up of Council members, or an on-going consultative assistance provided by an advertising or public relations company or individual professional.

If none of these is the case, a Council might make use of other agencies and resources which can facilitate the development and production of messages for a given channel and audience. For example, UAFs, educational media centers in public schools or universities, prison print shops, HEW regional communication programs, and state government media or public information offices should be contacted. Another facilitator might be consumer groups. Audette (1973) suggested that DD Councils

should consider contracting the development and production part of programs to local groups such as ARC, UCP, and Epilepsy. Of course, the final determination as to who will coordinate the program will depend largely on such factors as availability of local talent, regulations, purposes, and resources.

It is a good idea to have made media contacts prior to execution. This means that the coordinator should contact such persons as newspaper editors, TV and radio public service directors, and photographic studio personnel.

Executing the Plan

Even with someone responsible for coordinating the development and execution of the public awareness efforts, a Council must continue to explore programmatic alternatives, keeping money and time in mind. Additionally, it should strive for program consistency, clarity and credibility. Furthermore, it should seek long-term exposures, Council input, and a good mix of delivery channels.

After a plan has been conceptualized, the Council is ready to implement it. Read (1972) offers some execution suggestions.

Step 1. Budget time and money for each of the communication activities called for in the plan, and work up a calendar of deadlines for those activities. When will the first news story be written, the first radio program be aired, the first television program be presented? What are the dates for the scheduled meetings, and when must the first planning session be held for each meeting or the series of meetings? When and how will the meetings be publicized?

Step 2. Plan schedules to meet the deadlines. With a realistic time budget, we should be able to estimate the number of hours needed each week to carry out the plan. If the number of required hours is unavailable, we must adjust the plan to fit the hours.

Step 3. Evaluate the plan after each step and make adjustments called for by the evaluation. Our

first meeting may have been so successful that subsequent meetings are not needed. Cancel them. We learn that the television station has changed its program schedule, and the show we counted on is unavailable. We must shift resources to other channels. Audience feedback indicates more misunderstanding of the problem than we anticipated. We may need an additional series of news stories. Step 4. Make a final evaluation and prepare a report on successes and failures for future reference. We can improve our efforts tomorrow only by applying the knowledge gained today. (p. 305)

Thus, public awareness planning and development is a very important vehicle for advocacy. Its overall purpose, of course, is to assist Councils to make the DD Act work, lead the way for changing peoples' opinions and ideas, notify citizenry of services available, induce "the system" to yield more resources, and stimulate the development of new and better services for handicapped citizens.

BIBLIOGRAPHY AND RESOURCE LISTING

Selected Bibliography for this Chapter

Audette, Bob. Presentation on public information, DDTA Chairman's Conference, Quail Roost, N.C., November 1973.

Nelson, Roberta. Presentation on public information, DDTA Chairman's Conference, Quail Roost, N.C., August 1973.

Paul, Jim. Working paper on Advocacy Potential of DD Councils, DDTA, Chapel Hill, N.C., April 1974.

Read, Hadley. Communication: Methods for all media. Urbana: University of Illinois Press, 1972.

Trohanis, Pat. (Editor) Public Awareness: Considerations for Planning and Advisory Councils on DD. Chapel Hill: DD/TAS, 1974.

Waldman, Leslie. Presentation on public information, DDTA Chairman's Conference, Quail Roost, N.C., October 1973.

Public Awareness Resources

Films (all 16 mm)

1. Medals (21 mins., color, 1971)

Available: Bono Film Services, Inc.
1042 Wisconsin Ave.
Washington, D.C. 20007

A fun film about mentally retarded children having fun at the Mid-Atlantic Special Olympics sponsored by the Joseph P. Kennedy Foundation.

2. Like Other People (43 mins., color, 1972)

Available: Perennial Educators
P.O. Box 236
1825 Willow Road
Northfield, Ill. 60093

United Cerebral Palsy Inc.
Youth Activities Dept.
66 East 34th St.
New York, N.Y. 10016

Also available: United Cerebral Palsy of Denver
2727 Columbine Street
Denver, Colorado 80205

The most sensitive and hard hitting film on the subject of normalization. A British made documentary of a young cerebral palsied couple who are in love and demand the right to emotional and sexual fulfillment.

3. Normalization--The Right of Respect (14 1/2 mins., color, 1973)

Available: Atlanta ARC
First National Bank Building--Suite 369
315 West Ponce de Leon Avenue
Decatur, Georgia 30030

The film discusses the principles on normalization, especially residential facilities, and focuses on developmentally disabled citizens in real life situations.

4. All My Buttons (28 mins., color, 1973)

Available: University of Kansas Audio-visual Center
Film Rental Services
746 Massachusetts St.
Lawrence, Kansas

A dramatization which cuts through many layers of society to see how each reacts to or ignores the principles of behavior management and normalization.

5. Look Beyond the Disability (30 mins., color, 1972)

Available: Media Support Services
Parsons State Hospital & Training Center
Parsons, Kansas 67357

The film was produced for TV for the Kansas DD Council to help locate developmentally disabled citizens in need of services, to alert citizens to their key role as a "pressure group", and to encourage communities to provide services locally, especially education.

6. The Hope and the Promise (25 mins., color)

Available: National Rehabilitation Association
1522 K Street N.W.
Washington, D.C. 20005

A slightly out-of-date and rather rosy view of rehabilitation, including a 19 year old retarded youth who rises (meteorically) from sheltered workshop, to maintenance assistant, to spot welder.

7. Something Shared (15 mins., color, 1974)

Available: NARC
2709 Avenue E. East
P.O. Box 6109
Arlington, Texas 76011

A new film on citizen advocacy which introduces the subject of advocacy and touches on the nature of the advocate-protége relationship.

8. A Light for John (22 mins., B&W, 1956)

Available: Film Library
Division of Cinema
University of Southern California
University Park
Los Angeles, California 90007

An old, dated, but still lyrical and moving portrait of a retarded adult and his mother trying to cope with the world emotionally and financially.

9. That's What It's All About (28 mins., color, 1974)

A brand new and exciting film produced at Denver University on normalization and the Colorado Hostel Program. For information on its future availability contact: Chris Winokur, Division of DD, 306 State Services Building, 1525 Sherman, Denver, Colorado 80203.

Video Tapes (all 1/2" EIAJ format)

1. NARC has several video tapes on advocacy available.
 - A. "Protective Services: History, Status, and Critique" Elsie Helsel (60 mins., B&W)
 - B. "Development and Operation of Nebraska's Youth Advocacy Program" Julie Meyerson (28 mins., B&W)

- C. "Description of Youth Advocacy Activities: Greater Omaha Youth Association for Retarded Children" Terri Freyer (6 mins., B&W)
- D. "Legal Rights of the Impaired" Henry Cobb (82 mins., B&W)
- E. "The Role of the Parent Movement Within the Context of a Functioning Citizen Advocacy Schema" Gunnar Dybwad (60 mins., B&W)

For complete details contact: NARC
2709 Avenue E. East
P.O. Box 6109
Arlington, Texas 76011

- 2. The National Institute on Mental Retardation of Canada also has a series of video tapes on advocacy. They are understandably reluctant to loan tapes to the USA, however, they will gladly sell or trade tapes.

- A. "Advocate-Protege Panel" Clark, (30 mins., B&W)
- B. "Brief Overview of Citizens Advocacy" Korn, (30 mins., B&W)
- C. "Judy and Linda--An Advocate/Protege Relationship" (B&W)

For complete details contact: NIMR
4700 Keele Street
Downsview (Toronto)
Ontario, Canada M3J 1P3

Other Television

- 1. Larry (90 mins., color) a made-for-television movie about a 26 year old man who has spent all his life in an institution before it is discovered that he is not retarded. It is available as a film. For details contact the Learning Corporation of America, 1350 Avenue of the Americas, New York, New York 10019.

Slide-Tape Programs

1. Special People--Special Needs (14 mins.)
An introduction to the North Carolina Council on Developmental Disabilities and its work, focusing especially on the Community Profile, a community by community survey of all services for the developmentally disabled. Contact: Robert Denny, North Carolina Dept. of Human Resources, Council on DD, 526 Cooper Memorial Health Building, Raleigh, N.C. 27603.
2. Texas Slide-Tape Program (12 mins.)
An introduction to the Texas Developmental Disabilities Council and its work. The show is also available in a "three screen spectacular" version. Contact: Jack Leath, Texas Dept. of Mental Health and Mental Retardation, P.O. Box 12668, Capitol Station, Austin, TX 78711.

Print Materials

1. Newsletters are put out by several states and some planning regions within states. Two representative examples are:
 - A. Stepping Stones for the Developmentally Disabled of Tennessee. Contact: Polly Roddy, Editor, Stepping Stones, Tennessee Planning and Advisory Council for DD, 300 Cordell Hull Building, Nashville, Tennessee 37219.
 - B. Spotlight. Contact: Wisconsin Council on DD (Donald Eib, Council Chairman, and Editor), One West Wilson St., Room 540, Madison, Wisconsin 53702.
2. Informational brochures are also widely used--some representative examples are:
 - A. "Services for Persons in Virginia with Developmental Disabilities" Contact: Developmental Disabilities Planning and Advisory Council, Travelers Building, Suite 400, 1108 E. Main Street, Richmond, VA 23219.

- B. "The Developmental Disabilities Council Puts It All Together" Contact: New Jersey DD Council, 169 W. Hanover Street, Trenton, NJ 08625.
- C. "Council on Developmental Disabilities in North Carolina: Community Profiles" Contact: Council on DD, Dept. of Human Resources, 526 Cooper Memorial Health Building, Raleigh, N.C. 27603.



Legal Developments

The lot of developmentally disabled people has been discouraging; indeed, it has been depressing, when seen through a lawyer's eyes.

The law of Ancient Rome is the first reported law dealing with developmentally disabled persons, particularly the mentally handicapped; its primary concern was with their property, not their person, with their wealth, not their welfare. From the time of the Caesars, through the Age of Barbarism, through the Middle Ages, through the Renaissance and Enlightenment, into the Age of Revolution, and even as late as the Age of Colonialism, the law -- in all its majesty -- addressed itself principally to the custody and management of the property, not the person, of the developmentally disabled and mentally handicapped. Even as late as the eighteenth century, when state institutions were first created for the detention of persons dangerous to themselves and others, the sharpest focus of the law was with their property, and then with detention and isolation, not treatment and rehabilitation. Due process was available -- only when a person's property was at stake, not when his liberty was in jeopardy.

It was not until the nineteenth century that the law's principles of detention and isolation were

ameliorated by a humane concern for treatment, therapy and rehabilitation. Until then, developmentally disabled persons had been tortured, burned, exorcised, sold at market, segregated, isolated, ignored and only rarely valued or treated. They had been referred to in the law as "homo furiosus", "non compos mentis", idiots, lunatics, abnormal, subnormal, crazy and insane.

They were so treated by society, under its laws, not solely because they were inherently less able, but because they were different. They were described in words with the greatest perjorative connotation, words that stigmatized them in the eyes of the law and reflected society's inhospitable attitude toward them. Our Puritan forefathers treated them in contemplation of the law no differently than beggars -- persons to be excluded from the society of normal men and to be driven out of towns, persons worthy only of the tiniest morsels that might trickle down from the public or private table, persons no different from the meanest suppliant for whatever alms we might give. Except when they owned property, they were treated, in the words of Alexander Solzhenitsyn, as nonpersons.

This brief history is not remarkable, nor is it history in the sense of describing a condition of our past, for the development of the law as it affects the mentally disabled has depended on three factors: (1) the extent of medical knowledge about the etiology, care and treatment of the mentally disabled; (2) the degree to which the politically organized community has acknowledged its responsibility for the care and treatment of its afflicted citizens; and (3) the legal profession's awareness of the social realities of developmental and mental disability and the acuteness of its concern for those who have neither relatives nor friends to safeguard their rights. In historical perspective, these three factors have developed in mutual dependence and agonizingly, slowly and uncertainly. They are in a developmental stage still.

To prove the point that the law of the developmentally disabled person is in a developmental stage -- indeed, is at a vital point of development -- it is not

necessary merely to count the number of lawsuits brought on behalf of the handicapped, to examine the program content of professional meetings (where lawyers are now included), to review the spate of legislation enacted since the years of John F. Kennedy's presidency, or to count the millions of dollars we are investing in developmental disabilities programs. It is, instead, only necessary to examine the legal discriminations that now still exist against developmentally disabled persons.

The handicapped are denied those constitutional rights that each and every other one of us has. When they are institutionalized, they are denied rights to freedom of movement, association, speech, expression, privacy, and to acquire and hold property; they do not enjoy freedom from involuntary servitude, cruel and unjust punishment, and the massive curtailment of their liberty. When not institutionalized, they are denied rights to work or be paid a minimum wage, seek and find housing, vote, marry and procreate, and have equal access to the public and private benefits most of us take for granted - education, employment, housing, nonexperimental medical care and even basic medical care, protection from sterilization, protection from stereotyping and classification in education, and protection from the extraordinary penalties of the criminal law. They have been and still are segregated, isolated, institutionalized, and made wards of the state without their or their parents' consent. Ironically, they are forbidden to contract, yet they are held liable in tort, and made culpable under our criminal laws. They are discriminated against in almost every conceivable way by the public and private sectors of our abundant economy, and the law has not yet curbed these outrages.

All of this has happened and continues to happen, despite the fact that developmentally disabled persons typically have committed no crimes, except the crime of abnormality, and despite the fact that they have represented no menace to society, except the menace of difference. It has happened and continues to happen on the theory that they should be involuntarily confined for their own sakes so they may get treatment, and for the protection of society. Yet they are not treated, and it is

not clear why society should be protected from them. They are little valued in institutions, except they are worked without pay or for less-than-minimum wage. They are thought to be different and are so treated under the law, yet we cannot quantify their differences when it comes to their fondness for ice cream, their emotional needs for love, their physical needs for care, their human capacity for laughter or tears, or their sense of physical or emotional injury. When we institutionalize them, we deny them more than the rights guaranteed to the rest of us by the federal constitution. We deny them the companionship of normal friends and relatives; we deny them the opportunity to follow the examples of the best, or worst, of us; and we deny them the opportunity to lead the kind of life promised to all of us in a majoritarian democracy -- the rights to life without unnecessary interference, liberty without unwarranted restraint, and the pursuit of happiness by equal access to the opportunities of the public and private sectors. In the words of President Kennedy, we have relied on "the cold mercy of custodial care", when we should have developed "the open warmth of community concern and capability." We have traditionally resorted to Social Darwinism in law and economics, with the wholly predictable result that developmentally disabled persons have been the ultimate and inevitable losers. We have traditionally relied on theories of a competitive society instead of a rights-entitlement society, and the law has sanctioned these theories.

* * *

It is argued, and with great force, that persons who are developmentally disabled are, in constitutional terms, a "suspect class", that is, "a discrete and insular minority" without power to affect what happens to them. Like the aliens, blacks, and illegitimates, they bear the stigma of inferiority, the badge of opprobrium, and the unchangeable, guiltless trait of unfortunate birth. In the words of Justice Powell, like other suspect classes, they have been "saddled with . . . disabilities, or subjected to . . . a history of purposeful unequal treatment, or relegated to . . . a position of political powerlessness" (Note 1) as to justify special protection from majoritarian processes. They have been denied substantive due

process as guaranteed by the federal constitution, if we understand due process to "represent . . . a profound attitude of fairness between man and man, and more particularly between the individual and the government" (Note 2). They have been punished for the guiltless status of being disabled; they, like the illegitimates, have been punished without guilt or fault. They have been the victims of our forgetfulness -- perhaps of our repression -- of the warning of the courts that "How we treat these particular individuals determines, to a large extent, the moral fiber of our society as a whole, and if we trespass beyond the bounds of decency, such excesses become an affront to the sensibilities of each of us" (Note 3). They have been treated as nonhumans, as nonparticipants in the human race, as objects to be toyed with and discarded. They have not been accorded the "dignity of man" (Note 4).

Yet we can, today, take temporary solace. Medical advances abound in diagnostic, treatment, and rehabilitation techniques. A politically organized community, its moral sensitivities made keener and its ambitions whetted by the partially but suprisingly successful onslaughts against legally sanctioned racism and legally perpetuated poverty, is in the initial stage of a new war against old injustices. And the legal profession is more acutely concerned about the legally friendless handicapped person than ever before. These traditional allies are mounting an attack on a host of legal and economic discriminations against the developmentally disabled person. They are changing the traditional role of the developmentally disabled person from that of alms seeker and supplicant to that of litigant and victor in questing after and gaining the legal recognition of rights long possessed by everyone except the handicapped. They are asserting that the developmentally disabled are no less human and no less worthy of dignity on account of their disability, and thus are no less worthy of constitutional protection than the "normal" person. It is their assertion of sameness in spite of difference that today undergirds the law and the handicapped.

* * *

The law has a strong bias against innovation and

change. The role of lawyer . . . his creative use of precedent . . . is to persuade us that what is new is really not new, but is, instead, an extension of old norms and beliefs. Thus, in the emerging law of the handicapped, the old established constitutional norms are being creatively applied to developmentally disabled people.

The norms are: (1) liberty - the right to be free from stereotyping, detention, and from curtailments; (2) equality - the functional equality that treats all persons with similar concern for their basic human sameness and dignity as individuals; (3) integration - the norm that allows room for differences, celebrates differences, and reinforces pluralities. Normalization does not mean making everybody alike, for none of us wants to be normal or like the other; it is instead, in the eyes of the law, affording the norms of liberty, equality, and individuation for the handicapped; (4) individuation and choice - the norm that values the right to be different, but, for the developmentally disabled person, the right to have a choice, to have access to the fruits of our government and society, and assistance in the realization of their fullest capacities.

* * *

The emerging models of developmentally disabled persons are having a profound impact on the law's views of these unfortunates. One model teaches that developmentally disabled persons are capable of development. This norm requires the law to reject the "custodial care" concept and to desist from labeling that is self fulfilling or self limiting.

Another model, normalization, means that developmentally disabled people should live in the least restrictive environments conducive to their maximum development.

A third, consumerism, requires that consumers and their advocates should be involved in planning, programming and decision-making, just as the DDSA Facilities Act of 1970 requires consumer participation and courts require it on human rights committees.

Still another model asserts that developmentally disabled persons have "human" rights. This model gives rise to bills of rights for patients, mandatory education of developmentally disabled persons, and constitutionally based litigation.

A fifth model argues that, when institutionalized, the developmentally disabled person should be institutionalized only in accredited places. Accordingly, accreditation standards are being developed in legislatures, courts, and administrative agencies.

A final model acknowledges that although technological advances may help developmentally disabled persons, they have rights not to be experimental subjects or to be unjustifiably or unnecessarily subjected to untested or questionable treatment modalities.

* * *

Three premises lie behind the new assertion of human rights, legally recognized and enforced on behalf of the developmentally disabled person:

(1) The developmentally disabled person has been subjected to legal, social, and medical discrimination, based on degrees of humanness, where humanness correlates with intelligence, the lack of intelligence being justification for such discrimination.

(2) The professional does not know best; his judgement must be independently tested, and his action on those judgements must be subjected to a rule of accountability.

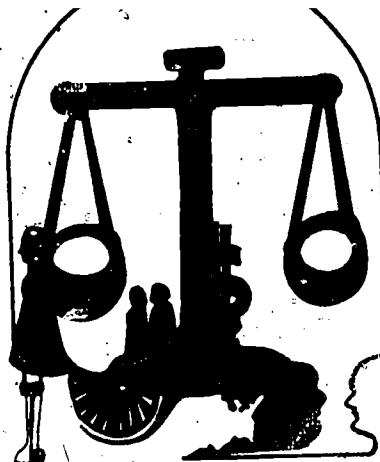
(3) The entire health and education delivery system, that is, the whole health and education infrastructure, that has been allowed to develop is rotten and should be reformed. Many persons think that legislative and administrative reform is hopeless, because the professionals intimidate the legislators by their expertise, and because the administrators are in the grips of the professionals. They think that the sole and most certain route of reform is through the courts, which, they hope,

will assist them in reconstructing these systems.

But litigation is only a tactic; it is only a door-opener, a catalyst to change. It may change the rules of proceeding with respect to the developmentally disabled person and it may have single-shot value. But it is unlikely that it will transform the power relationship between the developmentally disabled and nonhandicapped; it may not change public or private attitudes, and it may have some counterproductive effects and unanticipated and unwanted results. It needs to be accompanied by a massive change of attitude toward the developmentally disabled, a change that can be accomplished through both legislation and administrative rule-making. For only when public and private attitudes have changed will the law take on its greatest binding power and acquire its strongest sanction -- the power and sanction of public acceptance, the willing acceptance of what is now legally asserted but not yet publically accepted, the notion that, although the handicapped are less able, they are not less worthy.

REFERENCE NOTES

- 1) Rodriguez v. San Antonio, 411 U.S. 1, 28 (1973)
- 2) Joint Anti-Fascist Refugee Com. v. McGrath, 341 U.S. 123, 162 (1951)
- 3) Novak v. Beto, 453 F. 2d. 661, 676 (5th Cir., 1971)
- 4) Trop v. Dulles, 356 U.S. 86, 101 (1958)



Legal Issues

The term "legal advocacy", though used widely among those involved in the delivery of human services, commonly raises questions as to exactly what is meant. Does it refer only to activities in which a lawyer is involved? Does it include only those activities which involve adversary action in a court of law? Does "legal" imply an esoteric activity which can be engaged in only by a skilled professional and thus precludes the involvement of lay citizens acting on behalf of another? The responses to these questions are often, but need not be, cryptic and confusing. Advocacy includes any activity which involves a person acting on his own behalf or on the behalf of another to secure responses to perceived needs. Legal advocacy refers to such activities when they involve interaction with one of the three legally constituted institutions of government, i.e., legislatures, administrations, or courts.

For example, does a community have a group home? If it does, is there room for any particular child who needs care? Or does the home limit its residents to only one class of handicapped persons and restrict all others? If there is no home, is the cause a lack of funds? Are there restrictive zoning ordinances? What can be done if the handicapped in a community face all or some of these problems? An individual or group can approach the state

legislature and seek legislation establishing group homes, or request funding through local government. Community zoning ordinances can be challenged. Any of these activities would be a form of legal advocacy.

Suppose a group home exists in a community and the parent of a child who resides there, while wanting to use the service, experiences a problem. Sometimes the home parents seem to discipline unnecessarily the residents or unfairly restrict their visitors and other contact with the community. The natural parents have a discussion with the head of the agency which operates the home; the discussion leads to certain institutional guidelines protecting the rights of the residents. The parent has engaged in legal advocacy.

Further, assume the existence in a community of a group home in which the residents are well-treated, but the following situation develops. A child has been in the home for a year, progressing well. However, his parent suddenly receives word that the child has been transferred to a residential institution in another county for "misbehavior." The parent is shocked and immediately goes to the home to talk to the home parents. He receives no help. The parent calls the superintendent of the institution to which the child has been transferred. He is assured that the child is all right, but the superintendent insists that the child must stay at the institution. Finally, frustrated but still determined, the parent talks to the responsible agency head in the state capital, who apologizes for all the confusion but insists that there is nothing he can do since the matter was an appropriate administrative decision. At this point, the parent is so angry that he goes directly to the institution, physically removes his child and takes him home. A few months later, the parents realized that their home is not the best place for the child, but neither the group home nor the institution will take the child back. This time the parents go to court and sue the home operators for wrongfully transferring their child. This court action, of course, is legal advocacy.

As demonstrated by the above illustrations, legal advocacy can take many forms, the most common of which

the law-making by affecting legislation, law-making by administrative rules, and law-making by litigation in court. Of these forms is important and each has its proper place. In recent years, the public's attention has been focused on litigation. Important class action suits seem to be the solution to many, and these suits have been and will continue to be a great boon to the handicapped. But in the long run, in order to implement those legal rights enunciated in the courtroom, effective advocacy in the legislative and administrative areas will be necessary. All three areas are equally important. Developmental Disabilities Councils, carefully considering the needs of the developmentally disabled in their states, may wish to seek appropriate ways of supporting activities in any or all of them.

The purpose of the material presented here is to give a general introduction to the nature of legal advocacy to help Developmental Disabilities Councils develop legal advocacy programs. First, some general concepts of the law are discussed and an outline of the asserted legal rights of the developmentally disabled is presented. Next, some problems are discussed in detail. Finally, some specific suggestions are made as to how Developmental Disabilities Councils might engage in legal advocacy.

LAW AND THE HANDICAPPED: THREE KEY CONCEPTS

Many of the rights now being asserted on behalf of the developmentally disabled person derive from well-established legal principles as applied to new situations. Most of the recent cases involving the rights of the handicapped are based on federal constitutional principles. Many of the cases have involved both state and federal constitutional law, but this discussion is limited to the federal constitution, for it embodies the major principles also asserted under state constitutional claims. The key-stone principles all originate in the Fifth and Fourteenth Amendments: procedural due process, substantive due process, and equal protection. The Fifth Amendment makes these principles effective against the federal government, the Fourteenth Amendment against state and local governments. These legal maxims are all designed to protect individuals against unwarranted governmental action, whether federal or state.

Procedural due process guarantees a person the right, and a meaningful opportunity, to protest and be heard before government may take action with respect to him. It is a rule that requires government to proceed in a certain way; it is a rule of fair play. For example, as in the case of the person who is transferred from a state-supported group home to a state institution, it may be that the state violated his and his parents' right to procedural due process. The stated reason for the transfer was "misbehavior." If procedural due process were guaranteed, it would mean that the parents are entitled to know about the planned transfer before it takes place and have a chance to refute the charges of "misbehavior" and thereby challenge the transfer decision. It could be that the "misbehavior" was only slight and did not justify a transfer, or that whoever reported the behavior was mistaken about its nature or effect or even about whether the resident himself was the actor. The right to due process gives the resident and his parents the right to show such facts and why the transfer should not occur.

Substantive due process signifies that there are certain rights and privileges that a state cannot arbitrarily take away from its citizens, and that government may not act unreasonably, arbitrarily or capriciously in the treatment of its citizens. Whereas procedural due process refers to how a government must act, substantive due process refers to what rights or privileges a state may deny or revoke and to the reasonableness of its action in pursuing its legitimate purposes. For example, it may be a violation of substantive due process to place the group-home resident in an institution even if the resident has been granted his right to procedural due process and he was found to have misbehaved. Thus, it may be that the misbehavior itself does not justify the transfer to an institution (substantive due process), and that how the state acts in this instance (procedural due process) would be irrelevant.

Equal protection guarantees handicapped persons the same rights and benefits all other citizens have with respect to government, unless the withholding of the rights or benefits is for a valid reason that justifies the government in singling out a certain person or class

of persons for treatment different from that which others receive. If there is no group-home in a community because of a restrictive zoning law, and if the particular law in question allows any sort of living arrangement at all in the community "except for the handicapped", there most likely is a denial of equal protection, since the handicapped are denied the same rights as other group-home residents without a valid reason.

OUTLINE TO ESTABLISHED OR EMERGING
LEGAL RIGHTS OF THE DEVELOPMENTALLY DISABLED
(including areas where legal advocacy may be needed)

The following outline of legal issues is not a definitive statement on the rights of developmentally disabled persons, but rather it is a survey of most of the important issues and is designed for easy reference. Some of the rights listed are well-established while others are recently asserted and not yet settled. While the outline speaks specifically to the rights of the developmentally disabled person, a few of the rights may involve problems more often associated with the mentally ill or other mentally disabled persons.

- A. The right to live (protecting developmentally disabled infants from euthanasia)
- B. Right to medical care (including right to refuse treatment and experimentation)
- C. Right to education
 - 1. Early education
 - 2. Appropriate education
 - 3. Right to fair classification and placement
 - 4. Compensatory education (including adults)
 - 5. Quality education
 - 6. Normalization of schooling (including transportation, barrier-free access to building,

recreational activities, etc.)

D. Right to lead a normal and decent life

1. A right to be heard in all important decisions affecting the developmentally disabled (procedural due process)
2. The political process: right to vote and hold office
3. Domestic Relations
 - a. Right to marry
 - b. Right to bear and raise children (including right to obtain or refuse family planning services, including sterilization and abortion)
 - c. Right to adopt
 - d. Right to sexual expression
4. Right to a suitable environment (housing, privacy, etc.)
5. Right to employment (without unfair discrimination)
6. Right to mobility (including transportation, barrier-free access to building, drivers' licenses, etc.)
7. Right to security (fair access to insurance plans)
8. Non-discriminatory access to community services
9. Right to affect their own lives
 - a. Access to the courts (including right to sue and be sued, right to be a

witness, to obtain legal aid, etc.)

b. Right to control own person and property (modification of the laws of guardianship, conservatorship, legal incompetency, and other "protective" legislation)

c. Right to contract

d. Right to make a will

e. Right to make a gift

E. Rights pertaining to institutions

1. The commitment process

a. Freedom from involuntary commitment

b. Freedom from indeterminate commitment

c. Freedom from unjust commitment (diminished responsibility for the developmentally disabled person in some crimes)

d. Right to an advocate (both adults and minors)

e. Right to least restrictive setting consistent with rationale for commitment

f. Freedom from charge for the cost of being institutionalized

2. Within the institution

a. Right to an advocate

b. Right to release

c. Right to a decent environment (including medical care, physical security, etc.)

- d. Rights to education and treatment
 - e. Rights to refuse treatment
 - f. Right to be free from peonage .. fair wage for work performed)
 - g. Other patients' rights: including right to privacy, right to sexual expression, right to correspondence and visitation, right to property within the institution, right to participate in the decisional process, etc.
 - h. Right to periodic review of need for institutionalization and of treatment plan
 - i. Right to be free from unjustifiable transfer
- F. Implementation of statutory, regulatory, and other legal rights by advocacy
 - G. Creation of new legal rights (by statute, administrative regulation, informal procedures, and litigation)

TWO LEGAL ADVOCACY NEEDS OF IMPORTANCE:
EDUCATION AND PATIENTS' RIGHTS
(as of June, 1974)

Two fundamental areas of legal rights which deserve the attention of advocates are educational rights and patients' rights. These two areas embody many of the hopes of developmentally disabled persons for legal and social equality. The eventual impact of the successful assertion of these rights on the lives of the developmentally disabled can only be surmised, but it is likely that such impact will be enormous.

* * *

A. THE RIGHT OF ALL HANDICAPPED CHILDREN TO AN EDUCATION

Education is an elusive concept. One of the

difficulties in asserting the educational rights of developmentally disabled persons has been in definition. What many advocates have described as education other persons have denounced as "mere trainable" behavior" and have insisted that such activity has no place in the "academic" setting of public schools. This conflict in definitions has begun to subside with the affirmation of a right to education.

In finding such a right, one court has defined education to include all learning activities, both academic and behavioral. The court declared that education includes "any plan or structured program administered by competent persons that is designed to help individuals achieve their full potential." MARC v. Md., Equity No. 100-182-77676 (Circuit Ct., Baltimore City, April 9, 1974).

How did this broad definition of education finally come to be recognized? The first major breakthrough in asserting the educational rights of all handicapped children came in two recent federal court cases. PARC v. Pa., 343 F. Supp. 279 (E. D. Pa. 1972), established the principle that all retarded children have a constitutional right to an equal educational opportunity in the public school system; Mills v. D.C., 348 F. Supp. 886 (D.D.C. 1972), extended this tenet to include all handicapped children. In addition, several state court decisions have upheld constitutional claims vindicating the educational rights of handicapped children. One such case, Wolf v. Legislature of Utah, 3rd District, Salt Lake County, Div. #182646, (Jan. 8, 1969), found both a state constitutional and a state statutory right to education. MARC found that a state statutory right exists and ordered its implementation. Furthermore, several states, in reacting to these and other cases, have adopted "zero-reject" education laws, providing additional statutory bases for the educational rights of all children.

It has been observed that the educational rights of handicapped children have been clearly established in a number of cases. How did these cases develop? And on what grounds were these rights sustained? The leading

cases of PARC and Mills are illustrative.

In PARC fourteen retarded children brought suit against the state of Pennsylvania for themselves and as representatives for all other retarded children in the state. In the Mills suit brought against the District of Columbia, the situation was similar except that the plaintiff class included all handicapped children, not just the retarded. Both suits involved similar concerns. Parents, their children, and other interested persons had become continually frustrated at the neglectful inattention to the education problems of the handicapped. Public officials in both the District of Columbia and the state of Pennsylvania had historically shunted aside handicapped children. A policy of persistent discrimination had developed. The retarded and other handicapped children had been excluded from public schools on the grounds that they were incapable of benefitting from the educational process. And the ones who were allowed into school were only there at the "beneficence" of local programming. Defendants in the Mills case admitted their affirmative duty to educate handicapped ones. There was always plenty of room for "normal" children but never enough for the "others". In the early 1970's, the frustration felt by concerned citizens had built up to an unbearable level. And then a dramatic change occurred. The doors of the public school systems were opened as the rights of the handicapped were successfully asserted through the federal constitution.

Two basic legal rights were utilized in the resulting litigation: procedural due process and equal protection. These concepts were discussed in Section Two with reference to their applicability to group home problems. In PARC and Mills, they have been applied to the public educational process. In both cases public officials excluded handicapped children from school. It was at that point, the point of exclusion, that due process and equal protection assumed significance.

In this exclusion process, two things were happening simultaneously. First, local schools did not have sufficient facilities, qualified teachers, and monetary resources to educate their handicapped children. Secondly, the process itself was arbitrary and myopic. Children who

did not "fit" into the normal stream of things were often rejected, but the process frequently failed to find a lucid reason for their lack of fit. Thus, it remained unclear whether the fault lay with the children or with the schools. This was the situation presented to the courts. Plaintiffs successfully argued that equal protection required that if public instruction is available to "normal" children, then it must be made available to handicapped children, and that procedural due process mandated a hearing and careful consideration of each child's abilities and needs before schools could classify the child "not normal" and place him outside the public school. In this fashion, PARC and Mills were able to establish the education rights of handicapped children.

While the above summary synthesizes the basic theory behind the right to education cases, three other concepts are significant enough to require separate treatment.

1. APPROPRIATE EDUCATION

In San Francisco, Chinese-speaking students were held to have a right to supplemental English-language training under Title VI of the 1964 Civil Rights Act. Title VI requires that there be no discrimination based "on the ground of race, color, or national origin," in "any program or activity receiving federal financial assistance." The U.S. Supreme Court declared that "students who do not understand English are effectively foreclosed from any meaningful education" and thus held that a failure to provide English language instruction to Chinese-speaking students violated the Civil Rights Act. Lau v. Nichols, U.S., 42 LW 4165 (1974).

A similar issue involving the need for a meaningful education arose in the context of asserting the educational rights of handicapped children. Both in PARC and Mills the right to an "appropriate" education was raised. In PARC, the parties' consent agreement provided that ". . . it is the Commonwealth's obligation to place each mentally retarded child in a free, public program of education and training appropriate to the child's capacity" [authors' italics]. And, in Mills, the court's judgment

stated that, in considering alternative educational services when excluding a child from school, such services must be "suited to the child's needs."

2. RIGHT TO FAIR CLASSIFICATION AND PLACEMENT

This right compliments the right to an appropriate education. Most of the recent right-to-education suits include claims based on the lack of fair classification and placement procedures. These claims are founded on the assertion that, when children are placed in the wrong educational environment, their education will suffer and thus injury will accrue. PARC and Mills recognized this problem and held that whenever a child is subject to a "special" placement, he is entitled to procedural due process to ensure that both his classification and placement are correct and justified.

Perhaps the leading case in this area is Lebanks v. Spears, Civil No. 71-2897 (E.D. La. April 24, 1973). By court-ordered consent decree, all New Orleans retarded children are entitled to certain procedural due process rights whenever classified for purposes of special placement. These rights include a complete evaluation of the child, an opportunity for the child and his parent to contest his classification and placement, the development of a special education plan, and provisions for periodic review of whatever placement is made of the child. These rights in toto are intended to guarantee the child's placement in the most appropriate educational environment so as to maximize his learning opportunities.

3. COMPENSATORY EDUCATION

Compensatory education refers to the education necessary to repair the harm done to a person who was previously denied his right to an education. The right to a compensatory education is applicable to both children and adults. It has only quite recently received mention in the case law. In Lebanks, the court ordered that education and training opportunities must be made available to retarded residents "over twenty-one (21) years of age who were not provided educational services when children." And, in a recent North Dakota case, the court, while not

settling the issue of compensatory education, did observe that: "Handicapped children are certainly entitled to no less than unhandicapped children under the explicit provisions of the [state] Constitution. Whether those who have been unconstitutionally deprived of education in the past have a constitutionally based claim for compensatory educational effort, we leave for future determination." In the Interest of G.H., a child v. N.D., Civil No. 8930, Supreme Court, N.D. (April 30, 1974). [Authors' note: this case found both a state and a federal constitutional right to an equal educational opportunity for handicapped children.]

At this point, a short comment on the role that San Antonio Independent School District v. Rodriguez, 411 U.S. 1 (1973), plays in the educational rights of the handicapped is called for. Many educators felt that when Rodriguez declared education not to be a fundamental constitutional right, the legal underpinnings of right to education suits were severely undercut. This has not turned out to be the case. Rodriguez is a school-financing case. The Court held that Texas' method of financing, though leading to differences in the amount of public monies available to local school systems, did not violate the 14th Amendment's equal protection clause. However, the Court expressly left open the possibility that total exclusion from publicly supported education would be unconstitutional:

Whatever merit Appellee's argument might have, if a state's financing system occasioned an absolute denial of education opportunities to any of its children, that argument provides no basis for finding an interference with fundamental rights where only relative differences in spending levels are involved and whereas is true in the present case - no charge fairly could be made that the system fails to provide each child with an opportunity to acquire the basic minimal skills necessary for the enjoyment of the rights of speech and of full participation in the political process.

Thus, although Rodriguez did find that education

per se is not a fundamental constitutional right, later right-to-education suits have successfully distinguished Rodriguez on the ground mentioned above, and to date Rodriguez has had no appreciable adverse affect on the movement to secure educational rights for the handicapped.

Although there are a number of other educational rights issues, the main components of right to education established in the case law have been outlined. A more comprehensive review of the educational needs of the handicapped is available from sources included in the accompanying bibliography.

* * *

B. PATIENTS' RIGHTS: WITHIN INSTITUTIONAL-RESIDENTIAL FACILITIES

The topics covered in this section will include only those rights which find some support in the case law. This will leave a number of important areas unmentioned. Many of the legal rights of institutional residents derive from state statutory law, as opposed to constitutional or case law. Therefore, interested readers are referred to their state's Mental Health-Mental Retardation agencies for applicable statutes.

The leading case is Wyatt v. Stickney, 325 F. Supp. 781; 334 F. Supp. 1341; 344 F. Supp. 373; 387 (M.D. Ala. 1972), appeal filed May 12, 1972 (5th Cir.) establishing a right to treatment. In Wyatt, the court ruled that the right to treatment is the constitutional right "to receive such individual treatment as [would] give each of [the patients] a realistic opportunity to be cured or to improve his or her mental condition." Although originally confined to mental illness, the case was later expanded to include the mentally retarded. [For the retarded, this right has been more appropriately called the right to habilitation.]

The right to treatment has been based upon a constitutional quid pro quo. The idea is that when a person is institutionalized for the purpose of care and treatment, then due process (and fundamental fairness) requires that

such treatment be provided in exchange for that person's loss of liberty. Judge Johnson put it thusly:

Adequate and effective treatment is constitutionally required because, absent treatment, the hospital is transformed "into a penitentiary where one could be held indefinitely for no convicted offense."

The Wyatt court ordered an elaborate and detailed set of institutional standards in order to implement this right (see bibliography for information on how to obtain a list of these standards). Three of these standards considered to be essential are: (1) a humane psychological and physical environment; (2) qualified staff personnel in sufficient numbers; and (3) individualized treatment plans for all institutional residents.

The right to treatment has been extended to cover a number of institutionalized persons in different settings. However, one question has remained: does the right to treatment apply to the voluntarily admitted resident as well as the involuntarily admitted resident? This is a key issue for developmental disabilities advocates, since the large majority of institutionalized developmentally disabled persons are ostensibly committed voluntarily. The answer to this question is not yet definitive, but there is considerable authority for the proposition that both the "voluntary" and "involuntary" residents possess coequal rights to treatment. Wyatt, 325 F. Supp. 781; Ricci v. Greenblatt, Civ. No. 72-469 F. (E.D. Mass. February 11, 1972). Also, in an important new case, a three-judge district court further minimized the legal difference between voluntary and involuntary commitments by declaring the Tennessee voluntary commitment procedure for the mentally retarded unconstitutional as lacking in due process. Saville v. Treadway, C.A. No. 6969, (U.S. D.C., M.D. Tenn. Mar. 8, 1974). This case lends credence to the assertion that the mere "label of voluntariness" is not enough to justify different treatment for institutional residents. All, not just some, are entitled to treatment.

In addition to the general right to treatment set

forth in Wyatt, other specific rights have also been established.

1. LEAST RESTRICTIVE ALTERNATIVE

Under its inherent equity power to effectuate its decision, the Wyatt court ordered that "no person shall be admitted to the institution [Partlow State School and Hospital] unless a prior determination shall have been made that residence in the institution is the least restrictive habilitation setting feasible for that person." [Authors' note: the Wyatt court ordered a number of specific institutional standards to guarantee the mentally retarded residents of Partlow State School and Hospital their constitutional right to habilitation. Some of the more important standards will be mentioned below]. Also, in a major new case involving Minnesota state hospitals for the mentally retarded, the court declared that the residents of those hospitals have a federal constitutional right to have the hospitals explore and seek to provide them with the least restrictive practicable alternatives to hospitalization upon their involuntary civil commitment. Welsch v. Likens, No. 4-72 Civ. 451, (U.S. D.C., Minn., Feb. 15, 1974).

2. RIGHT TO AN ADVOCATE

The Wyatt court ordered the establishment of a standing Human Rights Committee to guarantee that residents are afforded constitutional and humane habilitation. One function of the committee is to advise and assist residents who allege that their legal rights have been infringed upon.

3. RIGHT TO A DECENT ENVIRONMENT

The leading case is NYARC v. Rockefeller, C.A. No. 72-C-356-8 (D.C. N. Y., April 10, 1974). This case held that all residents of Willowbrook State School for the Mentally Retarded have a constitutional right to be free from harm. Among other things this right specifically includes the right to protection from assaults, the right to conditions conforming to "basic standards of humane physical and psychological environment." In Wyatt,

the right includes the rights to dignity, privacy and humane care.

4. RIGHT TO EDUCATION AND TREATMENT

As stated previously, Wyatt recognizes a right to habilitation. It further declares that institutional "residents shall have a right to receive suitable educational services regardless of chronological age, degree of retardation or accompanying disabilities or handicaps." Wyatt has been followed in a number of other cases; however, there is one leading case to the contrary. Burnham v. Georgia, 349 1335, (N.D. Ga., August 3, 1972), appeal filed August, 1972, C.A. No. 72-3110, is a class action, similar to Wyatt, filed against six Georgia institutions for the retarded and the mentally ill. This case was dismissed upon defendants' motion, and the court failed to find a federal constitutional right to treatment. Wyatt and Burnham were consolidated for argument on appeal. Oral argument was heard on December 6, 1972, before the Fifth Circuit, but at this time the court has not yet rendered a decision.

Even though Burnham is contra, the right to treatment has found considerable support in the case law after Wyatt. The highest federal court to date to rule on the question of treatment has answered in the affirmative. Donaldson v. O'Connor, 42 LW 2577, (5th Cir. April 26, 1974) has declared that any nondangerous person who is involuntarily civilly committed to a state mental hospital has a constitutional right to such treatment as will help him to be cured or to improve his mental condition. Welsch v. Likens held that the institutionalized mentally retarded of Minnesota have a constitutional right to receive minimally adequate care and treatment. Further, the Welsch court specifically stated that "regardless of their ultimate dispositions by the Fifth Circuit, . . . Wyatt, rather than Burnham, should be followed here [in Minnesota]." The treatment concept has also found support in situations not involving the mentally ill or the retarded; it has been extended to the commitment of youths to juvenile detention centers. Martarella v. Kelly, 349 F. Supp. 575, (S.D. N.Y. 1972); Morales v. Turman, C.A. No. 1948 (D. C. Tex. August 31, 1973).

5. RIGHT TO REFUSE TREATMENT

The right to refuse treatment is derived from the established legal notion that no medical treatment may be given to a person without his freely-given and informed consent. Areas where this right proves to be particularly important include sterilization, psychosurgery, shock treatment, and excessive use of psychotropic drugs. Wyatt mandated that "residents shall have a right to be free from unnecessary or excessive medication", and that "behavior modification programs involving use of noxious or aversive stimuli shall be reviewed and approved by the institution's Human Rights Committee and shall be conducted only with the express and informed consent of the affected residents." Similar limitations were put upon the use of seclusion, electro-shock, and physical restraints. Prison cases which establish the right of experimental subjects to refuse treatment, Kaimowitz v. Michigan, C. A. 73-19433 - AW (Circuit CT., Mich., 1973); Knecht v. Gilliam 488 F. 2d C. A. 8-1136 (1973) arguably are applicable by analogy to the institutionalized developmentally disabled. Some authority for this proposition arises from NYARC v. Rockefeller, where the court stated that "... they [Willowbrook residents] must be entitled to at least the same living conditions as prisoners."

6. RIGHT TO BE FREE FROM PEONAGE

Both the Thirteenth Amendment and the Fair Labor Standards Act guarantee the institutional resident a salary for work performed. A recent case required that the U.S. Labor Department begin enforcing this right. Souder v. Brennar, C. A. No. 482-73 (U.S. D.C., D.C., Nov. 1973). Wyatt declared that no resident may be required to perform institutional-maintaining labor, and if he chooses to perform such labor he must be paid a minimum wage in accordance with FLSA.

7. INDIVIDUALIZED TREATMENT PLANS AND PERIODIC REVIEW

As a part of the resident's right to habilitation, Wyatt calls for an individualized habilitation plan for each resident based upon a thorough evaluation. This plan is to be continuously reviewed by the institution

and modified as necessary. Periodically, each resident is to undergo a comprehensive reevaluation.

8. RIGHT TO BE FREE FROM UNFAIR TRANSFER

Baxstrom v. Herold, 383 U.S. 107 (1966), held that when the state of New York tried to commit a prisoner at the end of his prison sentence to a mental institution, it had to afford such person the same due process rights as other civilly committed patients. This case may have limited applicability to the rights of the developmentally disabled, but it can be argued that institutional residents are entitled to some sort of due process whenever they are transferred to a new facility functionally different from that to which they were originally committed e.g., this may apply to a juvenile center resident being transferred to an institution for the retarded or vice versa.

9. OTHER PATIENTS' RIGHTS INCLUDE:

a) Right to affect their own lives: Wyatt declared that "no person shall be presumed mentally incompetent solely by reason of his admission or commitment to an institution [unless expressly so provided by state law]."

b) Right to confidentiality: "All information contained in a resident's records shall be considered privileged and confidential." Wyatt.

c) Right of access to a resident's records: "The guardian, next of kin, and any person properly authorized in writing by the resident shall be permitted access to the resident's records." Wyatt.

d) A resident's access to an attorney and the courts: a Sixth and Fourteenth Amendment right. Gould v. Miller, No. 72 Civ. 3255 (S.D. N.Y.), 6 Clearinghouse Review 510 (1972), held that mental institution patients are entitled to be interviewed by their attorneys privately, in complete confidence. Also, for prison cases argumentatively applicable by analogy, see gen., Goodwin v. Oswald, 462 F. 2d 1237, (2nd Cir. 1972); Via v. Cliff, 470 F. 2d 271, (3rd Cir. 1972).

e) Right to personal correspondence: A recent Supreme Court case recognized at least a limited right of prisoners to use the mails and is applicable to institutions for the developmentally disabled by analogy. Procunier v. Martinez, 42 LW 4606 (1974). Wyatt recognizes the right of residents to send and receive mail and to telephone communication.

10. POST-DEINSTITUTIONALIZATION ASSISTANCE

"Each resident discharged to the community shall have a program of transitional habilitation assistance." Wyatt.

LEGAL/LEGISLATIVE PROGRAMS THAT DEVELOPMENTAL DISABILITIES COUNCILS MAY WANT TO INITIATE

In outline form, this list suggests some of the activities that Councils might want to undertake in the area of legal advocacy.

1. Areas of Comprehensive study, law revision:

Special education law

Treatment-rights law

Guardianship

Sterilization

Zoning

Commitment procedures

Deinstitutionalization procedures

Confidentiality of records

2. Consumer-directed action:

a) Creation or enlargement for greater consumer input in:

- i. permanent legislative committee on exceptional persons
 - ii. permanent legislative-agency study commission on exceptional persons
 - iii. institutional human rights committee
 - b) Development of legal and paralegal advocacy systems and personnel: identify, use, develop legal resources
 - c) Training of consumers and service-delivery agencies in legal rights of exceptional persons
 - d) Development of consumer check lists, guidebooks, "road maps"
3. Agency-directed action:
- a) Review and revision of administrative, agency rule-making power, rules, and regulations
 - b) Training of agency personnel in legal rights of developmentally handicapped persons

SELECTED BIBLIOGRAPHY

1. "Mental Retardation and the Law", by Paul Friedman.

This is a quarterly summary of all litigation relating to the Rights of the Mentally Retarded. It is published and distributed by the DHEW, and is available upon request from the Office of Mental Retardation Coordination, 3744 HEW North, Washington, DC 20201.

2. Newsline is published monthly by the National Center for Law and the Handicapped. It is a brief update on recent developments in law and the handicapped.

3. "A Continuing Summary of Pending and Completed Litigation Regarding the Education of Handicapped Children", ed. by Alan Abeson, SFICEC.

This booklet includes both recent and old cases. Its primary focus is directed to education. It is available from the Council for Exceptional Children, 1920 Association Drive, Reston, VA 22091.

4. Clearinghouse Review, published by National Clearinghouse for Legal Services, 500 N. Michigan Avenue, Suite 2220, Chicago, IL 60611.

This is perhaps the most comprehensive publication on the legal rights of the disabled and disadvantaged. It is available at most law school libraries.

5. State Law and Education of Handicapped Children: Issues and Recommendations

This is the CEC model right-to-education statute. (See Item #3 for address).

6. The Mental Retardation part of the District Court's Wyatt opinion contains 49 individual standards or guidelines. It is available from the Office of Mental Retardation Coordination, U.S. Department of HEW, Washington, DC 20201.

7. The Mentally Disabled and the Law, ed. by Samuel J. Brakel and Ronald S. Rock, the University of Chicago

Press, Chicago, Ill. 60637 (1971 edition) is a standard reference work on the legal rights of the mentally disabled. Included are sections on commitment, incompetency, sterilization, guardianship, and criminal law.

8. A Handbook on the Legal Rights of the Mentally Retarded [in Pennsylvania], by the Pennsylvania Association for Retarded Citizens, 1974, is a good guide for groups who may be considering similar handbooks in their own states.

9. Silent Minority, the President's Committee on Mental Retardation, Washington, DC 20201, provides an excellent discussion of the legal rights of the retarded within an advocacy format (also, interested persons are given specific suggestions as to what they can do).

10. Basic Rights of the Mentally Handicapped, by the Mental Health Law Project, is a thorough introduction for lay persons into the rights of treatment and education.

11. Legal Rights of the Mentally Handicapped, Eds. Bruce J. Ennis and Paul R. Friedman, published by Practising Law Institute, 1133 Avenue of the Americas, New York, NY 10036, 3 vol., 1973. This is the most comprehensive single resource on the legal rights of the mentally handicapped. It is suitable for both lawyers and lay persons.

OTHER RESOURCES

- 1) Mental Health Law Project
1751 N Street, N.W.
Washington, DC 20036

MHLP is engaged in an effort to define and implement the rights of the mentally ill and mentally retarded through a program of litigation, education of the bar and the public, and related activities.

- 2) National Center on Law and the Handicapped
1235 N. Eddy Street
South Bend, IN 46617
(219) 288-4751 or 2

NCLH is concerned with all activities affecting the legal rights of the handicapped, but has, in the past, specialized in the area of right to education.



Deinstitutionalization

The purpose of this chapter is to develop a framework for (1) understanding deinstitutionalization, (2) developing policies, plans and programs that accomplish deinstitutionalization, and (3) suggesting possible implication for the DD Council's involvement in this process.

The material is divided into three sections. In the first section, the process by which institutionalization is accomplished is described and discussed in terms of those characteristics that (1) work in the disinterest and (2) those that work in the interest of people. The examination of the process is limited to those aspects of the problem that relate to developmentally disabled persons. Deinstitutionalization is defined as the process of countering institutionalization so as to reduce or eliminate those forces that unnecessarily compromise the rights and the integrity of the developmentally disabled as persons or as citizens.

In the second section, the position taken is that careful planning and program development is a central issue in countering institutionalization. That is, developmentally disabled persons are institutionalized, in large part, because there is no appropriate service or support system available when and where it is needed.

This results in inappropriate referrals and placements and further contributes to the "drift" of service systems into custodial and repressive patterns of care. The issues which are here considered include: 1) the importance of needs assessment in facilitating program planning; 2) the coordination of local, regional, and state service delivery systems, to optimally meet the needs of developmentally disabled persons; 3) the function of an advocacy mechanism; and 4) a view of current programming activities.

Drawing from material in the first two sections, the third section relates certain themes and conclusions to potential initiative functions of state Developmental Disabilities Councils.

DEINSTITUTIONALIZATION AND THE INSTITUTIONALIZING PROCESS

Definition and Perspective of Institutionalization

In recent years, DD Councils have become more sensitive to the problems of developmentally disabled persons and have become greatly involved with programs and activities designed to provide "normalization", "humanization" and "deinstitutionalization." "Institutionalization" has become the term within which negative connotations and feelings are embraced.

For the purpose of this discussion, let us use two simple definitions:

1. "Institutionalization" is the process of adaptation to an institution. The process represents a method and an attitude for dealing with human beings.
2. An "institution" is the physical place, with its staffing patterns and array of services and programs, which individuals may attend or within which they may live.

There are many implications of these definitions that could affect the way one thinks about institutional-

ization and the conclusions one reaches regarding it. If, for example, the institution is considered to be "good" and the process of adapting within the institutional system as leading to the best possible situation for the person being institutionalized, then the term could hold a positive connotation. If, however, the institution is considered to be "bad", is the process of adaptation to it also "bad"? When we use the term in a negative way, which is it that we resent: the process or the institution? We probably resent both, but it is important to distinguish between process and place. In developing strategies for dealing with dependent people, processes are going to be used to help them adapt to places. It will be essential that a careful check is kept on the methods and attitudes used in these processes.

Why is it that communities have continued for many years to build and tolerate institutions that are now generally considered as "bad"? If all institutions were "good", would placement of the developmentally disabled individuals within these institutions be our best answer?

Both "good" and "bad" institutions exist and are tolerated as an expression of the will and desire of the communities in which they are located. As currently constituted, and generally considered as bad, they are the product of historical evolution and persistent economic expediency. A major impetus for the current demand for change is the economic obsolescence of institutions as we know them. The cost of operating even the "bad" institutions is so great that the limits of state budgeting tolerance must soon be reached. Very few localities have been willing to provide the required high level of support for "good institutions" or drastically revise the use of current institutional support funds into new program forms. To continue to receive public support, the cost of operation of these institutions must stay within a limit which allows them to be ranked fairly high in the priorities of the voting public for the expenditure of tax dollars.

What criteria do we use to identify these people whom we decide should be removed from our midst? The following is one set of possible answers.

The multiple criteria used to select persons for placement fall into two major categories: social and functional. In the social category, the criterion is behavior which is considered inappropriate, unacceptable or threatening in relation to age, sex and subculture settings. In the functional category, the criteria is the degree of estimated or perceived competitiveness, productivity or dependence for age, sex and subculture settings. On careful consideration, it seems that these are valid criteria upon which to base the need for some form of intervention in the lives of handicapped or dependent persons. It appears that for some time to come we will use these criteria to select some individuals for institutional placement.

"Good" institutions for appropriate groups of people can exist, although these institutions bear little resemblance to what has generally been known thus far. In the variety of forms in which they can exist, the "good" institution probably is the "best" answer for some of the persons whom we identify as requiring significant intervention in their lives.

The Institutionalization Process

"Institutionalization" was defined earlier as the process of adaptation to an institution. This process has been divided into five steps which would seem to follow a logical sequential order. In reality, the various proposed steps may well occur in several different sequences. Each of the steps emphasizes methods and attitudes for dealing with human beings and avoids discussion of the physical environment in which these events may occur. It will be apparent that the word "adaptation" is not restricted to a time period and that the word "institution" does not refer exclusively to a specific type of residential facility.

Step 1. Identification and Labelling

The formal identification and public labelling of a person as being one of a group of persons with a disability like mental retardation, cerebral palsy, or epilepsy takes place at different times in the person's

life and for varying reasons. Early in life this identification and labelling may occur as part of seeking help. At school age, it may occur in response to the needs of the schools. Later in life, labelling may occur as a response to the community's concern with an individual's behavior or state of economic dependency.

Over many years the process of identification and labelling has become highly formalized, includes an elaborate terminology, classification system, and boasts a respected group of professional evaluators and labelers. The good intentions of this development are not doubted and the many important contributions that have resulted are acknowledged. Tragically though, labels carry stereotypes of expected personal qualities and behaviors that are deeply ingrained in the beliefs and attitudes of the community. Historically, these expected personal qualities and behaviors have been largely perceived in negative ways as "bad", "inferior", "dangerous", "immoral", etc. The labels have influenced development of services in a positive way as reflected in the many categorically-oriented services we have today. The associated negative connotations have had an adverse effect in that, ultimately, the quality of services we provide for people depends upon how we think about these people.

Step 2. Destruction of Self-Worth

How well we think of ourselves (self-worth) is largely determined by how we interpret what others think of us. It is a widely and strongly held concept of human development that the level of our feeling of self-worth has a critical effect on the quality of our adaptation to our life situation. The negative attitudes toward persons labelled as retarded, incompetent, or otherwise deviant, have been interpreted as preventing the development of a strong sense of self-worth and destructive of that which has previously been achieved. Thus, the already limited ability of the handicapped person to meet the demands of society is compounded by the further burden of a diminished sense of self-worth.

Step 3. Admission to an Institution

This is an event of almost unparalleled significance in the life of an individual. It may have positive as well as negative implications. It may be viewed as a successful achievement in many instances, such as entrance to a day school program. Such an admission may also be viewed as a further indication of society's perception of the individual as inferior or incompetent when that program clearly represents a further isolation from the general community. The separation from family, familiar people and accustomed places is usually considered traumatic. The impact of a sudden, profound change of environment taxes the strongest coping abilities. This phenomenon is greatest on admission to a residential program but can operate as well in day programs. The attitudes and feelings with which this occurrence is handled can greatly affect the quality of the experience.

Step 4. Regimentation

If construed as meaning the creation of an ordered, structured, life routine which insures that basic life necessities are met, then regimentation need not necessarily have a totally negative connotation. Historically, however, it has exceeded the simple good intentions for guarantee of provision of life necessities for the developmentally disabled.

Regimentation most frequently occurs in settings designed and staffed by people who are a part of that society which has identified and labelled the institutionalized person. Even in those situations with the most enlightened staff members, demands are usually made that the person adhere to policies and procedures of the institution. These include, at least:

- a. Being made part of a group whose activities of eating, sleeping, personal hygiene, and recreation are standardized to a rather rigid time schedule. An observed effect of this is that time becomes a meaningless abstraction.
- b. Enforced segregation of sexes varying from total and permanent to partial separation. Even partial segregation must be interpreted

as essentially permanent.

- c. Loss, or major diminution, of the prerogative of personal possessions, individual selection and style of clothing and grooming.

These and other policies and routines seem to be largely based on the premises that:

- a. These provide for the greatest efficiency and convenience of staff and facility.
- b. The residents are incompetent and incapable of making "proper" independent judgments or decisions.
- c. The residents are being protected from: (1) the outside world, (2) themselves, (3) each other.
- 1. The "moral standards" of the individuals and the public are being protected.

The need for some order and routine in the conduct of everyday life is generally accepted by all of us. The good intentions of protection and care of those who develop and implement such order and routine is acknowledged and respected. It is the reflection of the attitudes and feelings toward the individuals by those responsible for providing services that makes regimentation such a destructive part of the total process of institutionalization.

Step 5. Prophecy Fulfilled

The final step in the institutionalization process is accomplished when the person behaves in a manner fulfilling society's prophecy that he is "incompetent", "inferior", "immoral" or "bad." This represents the final justification for our behaviors and beliefs through the entire process, and for the process itself. Reaching this stage is considered as a "good" adjustment to an institutional setting, for it is usually accompanied by a state of docile regimentation and conformity to imposed

patterns of behavior.

With these five steps to institutionalization in mind, it is worthwhile to consider briefly some of the major consequences of the process for the developmentally disabled individual, the institutions, and the professionals who work within this system.

Consequences of Institutionalization

The consequences to the disabled individual have been those that we label as dehumanizing. The following are examples:

1. A general lack of sense of self-worth
2. A diminished ability to form deep, meaningful, lasting interpersonal relationships
3. Diminished sense of time perception and material value perception
4. Decreased to absent ability to make independent judgments of appropriateness of behavior for time, place and situation
5. High frequency of homosexual relationships

The consequences for the institutions have been well described and recorded by Blatt, Goffman and others. In essence, the institutions have represented an economical, clean, safe mode of permanently caring for large groups of people. Emphasis on the attributes of safety, cleanliness and economy have stifled the development of programs of habilitation and "normalcy" of life style.

The consequence for many of the professionals and allied workers who deal with developmentally disabled persons has frequently been their own institutionalization. Institutionalized staff and institutional systems have required labels for others and have become unnecessarily codified and regimented. Many institutional practices fulfill the prediction that the disabled will be socially incompetent. The disabled are frequently handi-

capped by lack of opportunity to learn adaptive social behavior, by not having a teacher or an environment that reinforces social skills, and sometimes by over protection based on underestimates of the potential of the disabled.

Definition and Perspective of Deinstitutionalization

If institutionalization is viewed as the process of adaptation to an institution, then deinstitutionalization may be seen as the reversal of that process--as a movement to insure that developmentally disabled citizens are afforded the opportunities of less restrictive community based living situations. The process of deinstitutionalization will require the continuation and expansion of the many diverse effects that have been started in the past two or three decades.

The major thrusts of these efforts are in three areas:

1. Modification of the identification and labeling processes to assure very early identification, functional evaluation, and concerned efforts to guarantee that services are provided,
2. The development of appropriate community services for all ages and stages of disability,
3. The dismantling of residential institutions as we know them now, and the development of new organizations of services and facilities for those who require assistance to live in society.

The following are aspects of the institution which are subject to change and are therefore vulnerable to both the modification of the institutionalization process and the initiation of deinstitutionalization necessary for the use of community alternatives.

1. Change in the mission of the institution.

- a. Since the mission of the institution is essentially set by the administrative unit of government responsible for it, initiation of change must originate and be sustained here. This is most critical since, with its full and unwavering support, changes in the institution at this level are almost impossible.
 - b. Institutional leadership and staff, bolstered and supported from above, must accept a new mission and the consequent changes in priorities, functions and programs required.
2. Sufficient support of the institution to allow it to change is essential. This may require significant new and additional funds to bring facility, staff, program and services to the level of acceptable standards. This presents the dilemma of improving what we ultimately wish to abandon. The institution cannot play its important role in deinstitutionalization and simultaneously be a part of the community array of services without some strengthening.
 3. Participation of the institution in the development of community alternatives. A number of the specific functions an institution may serve in this capacity can be named and will be discussed at length later in this chapter. A few major areas are:
 - a. Special programs to prepare persons for community entrance
 - b. Providing back-up care for community programs
 - c. Using its facilities for respite care and short-term training programs

Both fiscal and moral support for change must be present in the general public if change is to occur. The level of support or nonsupport is based largely on what the public expresses as its needs in a given area. What does the public feel it needs for the developmentally disabled? Does it need deinstitutionalization? We must proceed on the basis that it does. We must also continuously

monitor the relationship between our deinstitutionalization activities and the public acceptance and experience of those activities.

Hopefully, this section provides some understanding of the process through which developmentally disabled people have been systematically excluded from the social mainstream, and the recent movement toward reversing that extrusion process. Attention will be focused upon a number of issues which merit consideration by those responsible for the development and implementation of effective deinstitutionalization programs.

PLANNING AND PROGRAMMING FOR DEINSTITUTIONALIZATION

Assessing Community Needs

If programs are to be developed which are genuinely responsive to the needs of developmentally disabled persons, an important prerequisite to planning lies in the accurate assessment of these needs. Using a three dimensional framework of age, severity and sociological area, Stedman (1970) has developed a design for projecting needs, based upon a "hypothetical community." (See Table 1) Potential uses for the design are many: It has been helpful in examining strengths, weaknesses, and gaps in services; it has been useful in planning and facilitating the establishment of priorities where specific epidemiological data were not available; it has been useful, conceptually, in keeping the broad picture in focus; it has been helpful politically in "talking numbers" with legislators, county commissioners, and others who affect the distribution of revenues.

Using Part IV of Table 1; for example, it is possible to describe major services needed by the mentally retarded in the inner city. Stedman has suggested the following:

1. Diagnostic and counseling services for all of the 7,000 mentally retarded and their families;
2. Welfare, social and educational services to enable

the learning opportunities of the 624 mildly retarded preschool children, many of whom live in slums or in otherwise depressed circumstances.

3. Public health nursing and homemaker services to assist in caring for the 99 moderately and 25 severely retarded infants and young children in this population.
4. About 93 special education classes for the 1,683 mildly retarded school-aged children who, with specialized training, could become self-sufficient adult citizens.
5. About 27 special education classes for the 268 moderate or trainable mentally retarded children who, with the appropriate training, could become productive workers in supervised or sheltered work settings.
6. A day care, recreational center for the 60 severely retarded children of school age who would be unable to profit from formal school placement.
7. Vocational counseling, job training and placement services for the 389 retarded young adults who can contribute to their own and the community's welfare if given an opportunity to work in a supervised environment.
8. Specialized job training for the 3,145 mildly retarded adults over 25 who can take a productive place in our nation's economy.
9. Activity centers for the 563 retarded young adults and adults who may never take their full places as workers in the community, but who are socially important from the social and humanitarian point of view.
10. Residential centers to meet the needs of those 138 retarded young adults and adults with problems requiring supervision, care, and training so comprehensive as to require a 24-hour effort.

The hypothetical community model can be extended to include other populations, making it applicable to the

Table 1

Average Incidence of mental retardation based on 1965
census figures in four populations: 100,000 people.

Est. Incidence - 2% (Suburban)					
	Pre-School Under Age 6	School-age Age 6-19	Young Adults Age 20-24	Adults Age 25 and Over	Total All Ages
Mildly.....	179	480	111	849	1,609
Moderate....	28	77	18	143	266
Severe.....	7	19	4	35	65
TOTAL	214	576	133	1,027	2,000

Est. Incidence - 3% (Overall)					
	Pre-School Under Age 6	School-age Age 6-19	Young Adults Age 20-24	Adults Age 25 and Over	Total All Ages
Mildly.....	257	722	167	1,347	2,503
Moderate....	43	115	27	215	400
Severe.....	10	28	6	53	97
TOTAL	310	865	200	1,615	3,000

Est. Incidence - 5% (Rural)					
	Pre-School Under Age 6	School-age Age 6-19	Young Adults Age 20-24	Adults Age 25 and Over	Total All Ages
Mildly.....	446	1,202	279	2,246	4,173
Moderate....	71	192	44	358	665
Severe.....	17	47	10	88	162
TOTAL	534	1,441	333	2,692	5,000

Est. Incidence - 7% (Inner City)					
	Pre-School Under Age 6	School-age Age 6-19	Young Adults Age 20-24	Adults Age 25 and Over	Total All Ages
Mildly.....	624	1,683	389	3,145	5,841
Moderate....	99	268	62	501	930
Severe.....	24	66	15	123	229
TOTAL	748	2,017	466	3,769	7,000

Conversion Ratios

IQ Distribution Category	1965 Census - Age Group/Percentage Population				
	Category Under 6	6-19	20-24	25 and over	TOTAL
Mildly....	83.84	10.68	28.82	6.66	58.85
Moderate... 13.40					
Severe... 3.27					
TOTAL... 100.00					

Table 2

Incidence and Prevalence Low

Estimates of Developmental Disabilities per 100,000 People

	Total		Substantially Handicapped and Needing Special Services	
			All	Children Adults
Cerebral Palsy	500	15	300	200(+21) 100(+21)
Epilepsy	1000	1	100	
Mental Retardation	3000	3	325	152(+20) 172(+20)
Other Neurological Handicaps i.e., muscular dystrophy, speech and hearing, childhood stroke, etc.	10000		300	138 162

(1) DCPA Program Description Bulletin #2. (1 in 7,000 adults and 2 in 1,000 children)

(2) NINDS Neurological and Sensory Disabilities Estimates

(3) 10% of epileptics have uncontrollable seizures. E.F.A.

(4) Extrapolated from: Conley, Ronald, Economics of Mental Retardation, Chapter II, unpublished report at PCMR.

developmentally disabled. While there is considerable variance in the findings, Table 2 summarizes incidence projections on developmental disabilities. Sources of data are indicated. We have used the incidence estimates and projections applied to the total population for determining the number per 100,000 in order to make the data fit Stedman's projections more accurately.

It must be noted that these data are not equally reliable. Also, the data available on the distribution of mental retardation by age and sociological area were not available on the other populations. The data included here are based on low projections of developmental disabilities. There is also a distinction drawn between the projected incidence and the number of substantially handicapped persons who are likely to need special services. Empty cells either indicate gaps in information or a situation where an estimate would be too misleading.

These data are good general estimates that illustrate an approach to the assessment of the need to facilitate planning. In any given state, the data available in studies conducted there could sharpen the picture presented here.

Coordination of Service Delivery Systems

Another dimension of a program development model has to be the service array. While new services are frequently required to meet the needs of clients, it can be deceptive to think about one service apart from the array or "system" of services needed. The vested interest in a particular service system -- usually by bureaucrats and professionals, and the vested interest in a particular type or category of disability -- usually by parents and private organizations, contribute to the problems of coordination and duplication of services.

There is probably no ideal service system for developmentally disabled persons that could be projected as a part of a service-by-client matrix. The "fit" between the services as well as between one service and the client is important. The fit of the system with the

resources, attitudes, and culture of a place is important. The service is worth little unless it is a part of a delivery structure that makes it effectively available to all who need it, when they need it; and in a form that is acceptable.

Given concerns about the range, coordination, and delivery of services, we have developed a list of services that could exist. (See Display A) All of these services are not necessarily needed in one place. They are provided in Display A of this writing to illustrate the range of possibilities, not as a check-off list.

The first consideration of a service must be its responsiveness to the needs of developmentally disabled persons it is to serve. Beyond that, services need to be developed to fit the needs of a community in relation to services developed to meet regional needs, and those in relation to services to meet needs on a state wide basis.

As a general rule, the closer to the home community of a person the more specific and the more accurate the service can be. There is greater opportunity at that level for making the service accountable to individual clients. Conversely, the further from the real community, the more general and hypothetical are the needs being met. The more general the services, the more the individual's needs are lost or compromised.

"Statewideness" is a concept that accomodates the way revenues are distributed and government structures are arranged. It is an important concept for getting broad political support for better legislation and more assurances. In general, however, individual client needs are not met at the statewide system level.

In general, the closer home, the smaller, the more specific, the better. It must be quickly acknowledged that there are some needs that require such expensive technical help that a local community usually cannot afford to meet them. Also it is necessary, in some instances, to bring some groups of severely handicapped persons together, because the necessary facilities cannot be developed for such small numbers. A hospital for five

people, for example, would be difficult to sell to county commissioners. Here statewideness is important in program development.

It is important to distinguish between facilities and services, or programs. Services do not always require facilities. Ingenuity and care in planning can sometimes bring the "unaffordable" or "impractical" into the realistic sight of the community.

Anyone developing or lobbying for programs at the state level must have a clear rationale for why the client group cannot be better served in their own community. There are some justifications, but they are few. The distribution of resources should reflect consideration of where the best service might be provided. In general, only the very severely disabled person should be considered for treatment services outside his own home community, although they could be served close to their community if appropriate services are developed.

A fundamental consideration in evaluating the rationale for "serving" the person outside his own community has to do with whether the reasons relate primarily to the interests and welfare of the developmentally disabled person--or to bureaucratic expediency and vested interests that do not serve in the person's behalf. While this is a good guideline for assessing existing and proposed services, two things must be recognized. First, there is often a difference between what is said (promised) and what happens. This is usually not an intended deception. It is rather a realistic difference between things hoped for and things done. In talking about what we wish (plan) to have happen, we invariably underestimate the bureaucratic constraints on our implementations. This is also true of well-meaning and honest spokesmen for existing services. The "here is what we are doing . . ." is invariably only an approximation of what is happening. The Superintendent, for example, will say what he knows to be in effect based on (1) the information that comes up the line to him, plus (2) the data he obtained the last time he did a validity check on that information. The day-to-day experience of the institutionalized developmentally disabled person, however, is usually known

only to that person plus those who are with him during parts of his day, such as cottage parents and teachers.

The second thing to consider is that once programs obtain support and time in operation, they grow roots deep into the political system and the culture. This is the backdrop against which all interests in changing well-established institutional programs must be articulated.

The Advocacy Mechanism

The arrangement of services and bureaucratic support, from community to state levels, requires some system of monitoring and intervention to maintain equity and balance. If the developmentally disabled person is to be well served, his interest must be represented between and within services at each level and between levels. That is an advocacy function that helps keep the system honest. Accurate information is an essential principle in deinstitutionalization. It is essential for wise program development and program continuation decisions. It is also essential to maintain credibility with the public.

The advocacy function can be arranged organizationally in a variety of ways. Ultimately, it must push accountability in the direction of the client rather than the service system (the system will take care of itself). Advocacy should include the following: (1) a creed outlining the rights of developmentally disabled persons and standards for services, (2) a monitor to systematically collect information on how adequately developmentally disabled persons are served, (3) a feedback network to make information available in the system where correction can be made, (4) a power base for recourse in those instances where information and assistance do not stimulate any change, (5) an accountability system to keep the advocates honest, and (6) credibility with the consumer, the service system, and hopefully, the community.

Programming for Deinstitutionalization

There are currently many exciting programming efforts underway in state institutions and hospitals, community service agencies, and private organizations. No

agency or program has yet shown us the way and that will continue to be the case since deinstitutionalization suggests moving from many places simultaneously. No single professional wand can reach far enough. No single agency can bear total responsibility. Singleness of philosophy, service, or delivery system denies the very essence of the problem. While the course is uncharted, there has been some turning of institutional, professional, and bureaucratic machinery in the direction of some fixed points to guide the development of alternative courses and even alternative navigational systems.

Deinstitutionalization programs must ultimately accomplish an effective linkage, or liaison, between several social and professional systems for the specific purposes of accomplishing a reduction in institutionalization as described earlier in this paper. Those systems include the political power base; the resource structure with both real and potential energy (money, manpower...) for deinstitutionalization; the private sector, including organized lobbies, professional service providers, both private and public agencies; and the institutional structures.

Just as the institutionalizing system(s) is embedded in relationships between consumers and these various systems and structures, so deinstitutionalization programs must modify those relationships. Such programs will vary as much as those relationships vary. We do not know all the variables that affect institutionalization or how those variables work. We need a way to assess how the institutionalizing process works at each level we are trying to modify. If we are wrong in reading the process at the "local level", our regional design will not correct it. Somewhere short of assessing the variability in institutionalization between geographic areas, it is possible to describe some of the varying factors that require programmatic attention. Ten are described briefly below. They are not necessarily in any particular order and they are not mutually exclusive. They correspond generally, although not totally, to the topical outline of this book.

First, there must be an information system that

provides data on clients regarding needs and to clients or benefactors regarding resources. This system must also include evaluative data on programs. Second, there must be a decision-making philosophy and the accompanying machinery to: (1) effectively involve consumers or their representatives in the decision-making process, and (2) keep consumer-relevant decisions made as close to the consumer as possible, rather than higher in the bureaucratic service structure. Third, the deinstitutionalization program efforts must include attention to the legal and human rights of developmentally disabled persons. This must include making such rights known as well as correcting their denial. Fourth, there must be a free flow of information to the public about services and needs. Public education should be structured within a psychology of constructive involvement of those receiving the information. Fifth, deinstitutionalization activities must penetrate the attitudes, morale, and competencies of the staff who work directly with the developmentally disabled. In large institutions, for example, the direct care staff may be a source of some abuse. They are also a source of enormous advocacy potential which is frequently buried under bureaucratic messages of meniality and general lack of regard. Transformation at this direct care level is essential. Sixth, there must be a benefactor or advocate system of some type. Heber found the presence or absence of a benefactor to be the most crucial variable in successful deinstitutionalization. Seventh, there must be specific attention to the budget system and the process by which budgets are renewed or changed. If money is going primarily into institutionalization, substantial deinstitutionalization will not occur. Eighth, there must exist an accountability structure which, at a minimum: (a) keeps information current, valid, available, and flowing; (b) prevents the drift of decision-making upward and pushes it closer to the consumer or his benefactor; (c) provides procedural recourse for correcting abuse or denial of rights of the developmentally disabled as perceived by the developmentally disabled, his benefactor, or other person knowledgeable of advocacy needs; (d) provides active advocacy for constructive and immediate resolution of problems which seeks neither to embarrass nor intimidate. Such an accountability structure is certainly facilitated by, and

some would argue probably best accomplished by, third party involvement in monitoring, information flow, and advocacy activities. Ninth, community alternatives to institutionalization must exist. Group living, foster home, and sheltered work arrangements are a few of the essential community resources that prevent the need for institutionalization and make possible the reentry of the institutionalized person into the community. The development of effective community alternatives is certainly a cornerstone to the success of the total deinstitutionalization effort. Tenth, and closely related to that success, is the careful attention to the standards of both residential and community facilities.

As stated earlier, the program format for attending to each of these ten issues varies. There is no "best way" because the intervention must fit the ecology of the problem. Display B lists some programs known to the writers to have been successful in solving some of these problems. Display C includes a very brief selected bibliography on the topic of deinstitutionalization.

IMPLICATIONS FOR DEVELOPMENTAL DISABILITIES COUNCILS

The Developmental Disabilities Council has a unique opportunity as a planning body since both private and public membership represents developmentally disabled persons and the agencies that provide services to them. Major opportunities exist in the areas of deinstitutionalization and advocacy. This chapter has developed the view that deinstitutionalization is an effort toward correcting, reducing or stopping certain aspects of the process of institutionalization. We pointed out the problems in the ways services are arranged, in the narrowness of perspective on client needs and ways of meeting those needs, and in the tendencies of services to become separate and complete unto themselves, becoming more exclusive in their functions to the population they serve. We noted the deep discontinuities of purpose between services, the name (label) lines on which clients are passed from one system to another, and the ultimate cul-de-sac in the service delivery network, the state institution.

One antidote to institutionalization is providing

better integrated services. Another is to more effectively integrate the private sectors in planning service delivery and monitoring. A third is improved evaluation of the client/service match over time. The possibilities of a third party monitor of that match have been suggested. The third party monitor idea includes the prospect of bypassing usual bureaucratic information circuits in order to facilitate more effective planning at the state level. The needs have been implied for orchestrating without controlling, for adding perspective without co-opting, and for penetrating the ranks without sabotaging. The Council has in its very makeup and in its mission, implied if not stated, the opportunity to develop these advocacy functions and to contribute to the formulation of policies that reflect these values.

The Council must develop a posture of being near but not necessarily in the bureaucracy. If it gets buried under the portfolios, policies, guidelines, and regulations of agencies, its advocacy functions are compromised and over time the freshness it brings will become stale. It will just do the things good bureaucracies do. If it remains aloof from the agencies, and fails to get involved enough to understand the problems agencies face, it cannot develop realistic deinstitutionalization plans. Only by transcending the trust barriers with agencies, can councils serve as truly effective advocates. If power is an instrument for change, it is also threatening and can put people on the defensive, especially in state bureaucracies. The issue here is balance and approach in developing a working relationship with state agencies based on respect and appreciation for the complexity of the issues involved.

The Council can, by its own operation, model the integrative planning and advocacy functions. In asking others to "get together", the Council needs to demonstrate its commitment to "being together" with the others.

The Council must exploit its uniqueness: (1) for accessing information from outside channels, and (2) for sharing information directly with the citizenry, legislators and, occasionally, the judiciary.

Most specifically, the Council: (1) can determine how institutionalization works in its state, (2) develop a plan for reducing it by planning a better client/service match, (3) develop and institute a system to monitor the implementation of that plan and the on-going "matching", (4) develop a system for reducing the institutionalization process based on that information. The Council must maintain its own credibility as a viable arrangement in state government with ability to constructively influence opportunities for the developmentally disabled. Deinstitutionalization is only one example of the Council's advocacy potential. The Council's credibility can be maintained by remaining open and oriented to the diplomatic solution of problems, rather than becoming preoccupied with power-oriented strategies and political solutions.

The Council can help change the traffic pattern across service systems. It can help open up the institutional cul-de-sac. It can help change the reward structure for institutionalization, making it bureaucratically more profitable--speaking now of budgets and personnel--to deinstitutionalize. The Council can help get institutions out of a defensive posture. It can facilitate more effective involvement of private organizations in the solutions of the problems of institutionalization. The Council can help legislators and governors understand the scope of the problem so they might more effectively support institutional change and the need for resources to learn more about institutionalization and ways to reduce it. The Council can help the budget people understand the softer services base (training, liaison, etc.), as opposed to counting beds, as the basis for allocating funds.

The Developmental Disabilities Council, then, has enormous potential as an advocate for developmentally disabled persons and for a reasoning approach to deinstitutionalization. The issues are complex and must, in most cases, be confronted state by state. Each state Council has to develop its own style and the appropriate uses of its own resources to respond to the particular characteristics of its own state's service and consumer organizations, laws and resources. Each Council must ultimately find its own organizational and tactical means for being

accountable to developmentally disabled citizens and
their rights.

DISPLAY A

Programmatic Outline for Deinstitutionalization

- I. Prevent Substantial Handicap Which Might Lead to Institutionalization
 - A. Prevention incidence of developmentally disabled
 - 1. Research
 - 2. Genetic Counseling
 - 3. Family Planning
 - 4. Pre-, peri-, and post-natal care
 - 5. Nutrition
 - 6. Safer Environment: housing, lead-paint poisoning program, etc.
 - 7. Social services - i.e. education and training for family (prevent accidental or cultural developmental disabilities)
 - B. Prevent Need for Longterm Outside Help (even when developmental disability is present)
 - 1. Early intervention (i.e. PKU: screening and treatment)
 - 2. Societal education: provide both skills and motivation to care adequately for own
 - 3. Private insurance: catastrophic injury
- II. Alternatives to Institutionalization (DD present)
 - A. Family or individual support services
 - 1. Meals-nutrition

2. Environmental concerns: housing improvement services, chore services, etc.
3. Financial maintenance
4. Medical services (including early screening and identification; mental health services)
5. Information and referral services
6. Child education (community): a key component to deinstitutionalization
7. Home worker - childhood stimulation
8. Day care, head start, etc.
9. Parental and family education
10. Sex Education (to developmentally disabled person and family)
11. Parent Relief Services: baby sitting, temporary respite (vacation services)
12. Other social services: special services, companionship and recreational services, consumer protection and money management education, etc.
13. Employment Services: vocational habilitation and rehabilitation, transportation services, access to buildings, etc.
14. Community-consumer input (planning, services, etc.)
15. Volunteer-group advocacy
16. Legal advocacy
17. Penal-correctional services for the developmentally disabled in the criminal system

B. Community Alternatives

1. Adoption services
2. Foster homes
3. Follow-up services for deinstitutionalized persons
4. Mobile clinics
5. Ambulatory clinics
6. Group homes
7. Half-way houses
8. Community institutions
9. Alternatives to the prison system for the developmentally disabled population

III. Institutional Reform

- A. Development of a deinstitutionalization-oriented policy (planning)
- B. Public Education
 1. Improve institutional community interactions with goal of deinstitutionalization
 2. Re-conceptualize definition of deinstitutionalization, i.e., one component of community services continuum
 3. Family education: to encourage retention of emotional and legal responsibility for child
- C. Treatment and education (with goal toward deinstitutionalization)
- D. Staff Development
 1. Work enrichment programs

- 2. Staff input and advocacy
- 3. Staff politics (i.e. union problems)
- E. Patient input and rights
 - 1. Self-government, grievance committees, etc.
 - 2. Advocacy: legal and other
- IV. Legal Advocacy (areas where needed)
 - (See Chapter 10, p.153)

Note: The above programmatic outline, developed by Chris Pascal, is not intended as an endorsement of any particular program or programs by the author or DD/TAS. Rather it is to serve only as a list of possible programmatic alternatives to be considered by DD Councils in their planning and advisory role.

DISPLAY B

Program Development: Issues and Approaches

<u>Issues</u>	<u>Programs</u>
1. Client Information System	<ul style="list-style-type: none"> -Bringing It All Back Home -Child Advocacy Systems Project -Los Lunas Hospital and Training School -National Center for Law and the Handicapped, Inc. -Southwest Georgia Program for Exceptional Children
2. Consumer Oriented Decision-Making Arrangement	<ul style="list-style-type: none"> -Bringing It All Back Home -Child Advocacy Systems Project -Los Lunas Hospital and Training School
3. Legal Rights Orientation	<ul style="list-style-type: none"> -Bexar County Mental Health/Mental Retardation Center -National Center for Law and the Handicapped, Inc.
4. Public Information System	<ul style="list-style-type: none"> -Bexar County Mental Health/Mental Retardation Center -Child Advocacy Systems Project -Los Lunas Hospital and Training School

5.. Staff Reeducation
or Enrichment

-National Center for Law and
the Handicapped, Inc.

-Southwest Georgia Program
for Exceptional Children

-Bexar County Mental Health/
Mental Retardation Center

-Office of Developmental Dis-
abilities, Columbus, Ohio

-SEED Program, Sewall Reha-
bilitation Center

-University of Oregon Medical
School (UAF)

-Work Enrichment Program,
Western Carolina Center.

6. Benefactor (Advocate)

-Child Advocacy Systems
Project

-Los Lunas Hospital and Train-
ing School

-Parent Training Project,
Western Carolina Center

-Western Carolina Center Ad-
vocacy Project

7. Budgeting Model
or Procedures

-Bexar County Mental Health/
Mental Retardation Center

-Southwest Georgia Program
for Exceptional Children

8. Accountability Struc-
ture or Advocacy
System

-Bringing It All Back Home

-Child Advocacy Systems
Project

-Macomb-Oakland Residential Center

-National Center for Law and the Handicapped, Inc.

-Western Carolina Center Advocacy Project

9. Community Alternatives -Bexar County Mental Health/
Mental Retardation Center

-Bringing It All Back Home

-Child Advocacy Systems Project

-Los Lunas Hospital and Training School

-Macomb-Oakland Residential Center

-Mansfield Training School

-National Center for Law and the Handicapped, Inc.

-Office of Developmental Disabilities, Columbus, Ohio

-Project ZERO

-RISC (Reduce Institutionalization of Special Children)

-SEED Program, Sewall Rehabilitation Center

-Southwest Georgia Program for Exceptional Children

-University of Oregon Medical School (UAF)

10. Standards (Residential and Community)

-Bexar County Mental Health/
Mental Retardation Center-National Center for Law and
the Handicapped, Inc.-Parent Training Project,
Western Carolina Center

-Project ZERO

Addresses and contact persons for programs listed in Display B follow:

Bexar County Mental Health/
Mental Retardation Center
611 North Flores
San Antonio, TX 78205

Contact

Person: Ms. Carol Wilder

Bringing It All Back Home
Western Carolina Center
Enola Road
Morganton, NC 28655Gary D. Timbers,
Ph.D.Child Advocacy Systems
Project
Learning Institute of
North Carolina
1006 Lamond Avenue
Durham, NC 27701John W. Pelosi,
Ph.D.Los Lunas Hospital and
Training School
P.O. Box 208
Los Lunas, New Mexico 87031Joseph F. Mateju,
AdministratorMacomb-Oakland Residential
Center
36368 Garfield Road
Fraser, Michigan 48026David Rosen,
SuperintendentMansfield Training School
Brown Building
Box 51
Mansfield Depot, Connecticut 06251

James F. Williams

National Center for Law and
the Handicapped, Inc.
1235 North Eddy Street
South Bend, Indiana 46617

G. Linden Thorn,
Executive Director

Office of Developmental Disabilities
2929 Kenny Road B1046
Columbus, Ohio 43221

Lee Rubin,
Administrator

Parent Training Project
Western Carolina Center
Enola Road
Morganton, NC 28655

Cloret King,
Director

Project ZERO
420 Gaffney Drive
Watertown, NY 13601

Thomas A.
Coughlin, III

RISC Project
Johnson County Mental Retardation
Center
5900 Flint Street
Shawnee, Kansas 66203

Mrs. Ozella
Willis, Project
Director

SEED Program
Sewall Rehabilitation Center
1360 Vine
Denver, Colorado 80206

Diana Neel
Pefley, M.S.W.

Southwest Georgia Program for
Exceptional Children
P.O. Box 110-A
Ochlocknee, Georgia 31733

Mr. Harold Smith
or Mr. Bob Kibler

University of Oregon Medical
School
3181 S.W. Sam Jackson Park Rd.
Portland, Oregon 97201

Leroy O. Carlson,
M.D.

Western Carolina Center
Advocacy Program
Western Carolina Center
Enola Road
Morganton, NC 28655

Emma Jean Hogan
Frassrand

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Work Enrichment Program
Western Carolina Center
Enola Road
Morganton, NC 28655

Janet Nicholson

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DISPLAY C

SELECTED BIBLIOGRAPHY

- Blatt, Burton. Souls in Extremis, An Anthology on Victims and Victimizers. Boston: Allyn and Bacon, Inc., 1973.
- Conley, Ronald W. The Economics of Mental Retardation. Baltimore: The Johns Hopkins University Press, 1973.
- Dybwad, Gunnar. "New Patterns of Living Demand New Patterns of Service—Is Normalization a Feasible Principle of Rehabilitation." Luncheon Address for the International Conference on Models of Service for the Multi-Handicapped Adult. New York City, October 10, 1973.
- Heber, Rick F. and Dever, Richard B. "Research on Education and Habilitation of the Mentally Retarded", in Social-Cultural Aspects of Mental Retardation, H. C. Haywood (Ed.). New York: Appleton-Century-Croft, 1969.
- Hobbs, Nicholas (Ed.). The Futures of Children, Categories, Labels and Their Consequences. San Francisco: Jossey-Bass, 1974.
- _____. Issues in the Classification of Children, A Source Book on Categories, Labels and Their Consequences. San Francisco: Jossey-Bass, 1974.
- Holder, Harold D., Pelosi, John W., & Dixon, Rebecca T. How to Monitor Agencies that Serve Children, A Child Advocate's Manual. Child Advocacy Systems Project, Learning Institute of North Carolina (LINC), 1006 Lamond Avenue, Durham, NC 27701. August 1974.
- Joint Commission on Accreditation of Hospitals. Standards for Community Agencies Serving Persons with Mental Retardation and Other Developmental Disabilities. Accreditation Council for Facilities for the Mentally Retarded. Adopted July 25, 1973.

- Larsen, Lawrence A., Ph.D. Community Residences for the Mentally Retarded: Bibliography and Abstracts. These materials were prepared under a contract with the Developmental Disabilities Technical Assistance System, Room 300, NCNB Plaza, 136 E Rosemary St., Chapel Hill, NC 27514. Requests for reprints of abstract materials should be forwarded to DD/TAS.
- Maloney, Dennis. "Evaluation of Community-Based Treatment Facilities." Paper prepared for DD/TAS. Unpublished copies available from DD/TAS.
- Mercer, Jane. Labelling the Mentally Retarded. Berkeley: University of California Press, 1973.
- Paul, James L., & Neufeld, G. R. "Child Advocacy: Principles and Procedures," in Contemporary Treatment Approaches with Emotionally Disturbed Children, Bruce Saunders (ed.). Exposition Press, 1974.
- Pelosi, John W., & Johnson, Sandra. Advocacy for Your Child LINC Press, 1974. Available from the Learning Institute of North Carolina.
- _____, Paul, James L., & Neufeld, G. Ronald. Learning About Child Advocacy: The Child Advocacy Systems Project. LINC Press. Available from the Learning Institute of North Carolina
- Region IV Staff Development Conference on Institutional Reform, Columbia, South Carolina. September 9-11, 1973.
- Riddle, J. Iverson, & Larsen, Lawrence A. "Mental Retardation 1984," Conference Proceedings published by the Western Carolina Center, Morganton, NC.
- Scheerenberger, R. C., Ph.D. "A 'Realistic' Model for Deinstitutionalization," Superintendents Seminar. Sponsored by the Center for Developmental and Learning Disorders, Management Training Program, University of Alabama in Birmingham. Dallas, TX, March 21, 1974.

Sigleman, Carol K. (Ed.). "Group Homes for the Mentally Retarded," Research and Training Center in Mental Retardation, Monograph No. 1. Texas Tech University. Lubbock, Texas. August 1973.

_____. "Protective Services and Citizen Advocacy," Research and Training Center in Mental Retardation, Monograph No. 3. Texas Tech University, Lubbock, TX May 1974.

Stedman, Donald J. "Alternative Organization and Function of the State Council on Developmental Disabilities." A paper prepared for the first conference on State DD Council role at Quail Roost Conference Center, Rougemont, NC. August 29-31, 1973.



Epilogue

The body of this document was gleaned from a DD/TAS conference about advocacy for the developmentally disabled. Unlike most conferences, the participants did not just talk about problems. They developed strategies to solve problems, to meet their own needs at home, and to chart new directions for change.

Advocacy, as exemplified in this monograph, can be many things to DD Councils. It is their method of representing one's organization and the developmentally disabled. It is mostly hard work. Above all, it is to no avail, no matter who the advocate, if it is not a measured, systematic process whereby knowledge is transferred. Attitudes must be changed and barriers overcome by a strong persistent pressure, gentle but firm, based on data and competence.

People are usually of two minds on the topic. To some, advocacy is hearts and flowers, bleeding hearts, poetry, pity and depression. To others it is a harsh, adversary posture, defensive aggressiveness, pushiness and abrasion. Neither is the case. Advocacy is that proper mixture of passion and competence that generates a new, enlightened point of view based on fact and skill rather than simple faith and assertion.

Without passion, the energy and persistence required to work daily against the resistance to change and progress for the disabled is not possible. The enthusiasm necessary to generate new strength and determination in others cannot be communicated without the caring and sensible devotion to the task. Passion makes the small gains satisfying.

Without competence, passion is a trap. Without the knowledge, skill, data, facts, and understanding of problems and their solutions, all the passion in the world will never help the developmentally disabled.

Legislators, school board members, county commissioners, mayors, congressmen and many other individuals of consequence in the community require facts and the chance to change their attitude. New programs for the developmentally disabled take time, money and persistent people. Programs also demand sponsors, people whose ideas often need changing before they will back a new program--especially for handicapped persons.

Advocates can be effective. Their own passion and enthusiasm, laced with the information required to back assertions and requests, will prevail with others as no other strategy can.

The next decade will tell the value of the last fifty years of effort on behalf of the handicapped. The knowledge about the handicapped and their needs is far from complete, but our information is sufficient now to push successfully for change. Advocates must do that job. They must do it in a unique way. They must know and care for the rights of others. They must know and care for the persons they represent. When that zest is gone they must leave the field.

The goal of the DD/TAS conference and this document was to renew both passion and competence in the participants and readers. If that has happened, then developmentally disabled people have gained.

APPENDIX 1

APPENDIX 1

CONFERENCE ON INITIATIVE FUNCTIONS OF
DEVELOPMENTAL DISABILITIES COUNCILS:
STRUCTURE AND RATIONALE

DD/TAS organized a Conference on Initiative Functions of State Developmental Disabilities Councils in response to two needs. First, DD/TAS had received requests for assistance with tasks ranging from clarification of Council organizational position in State government, to implementation strategies for model programs. These requests, though differing markedly in technical expertise required, had in common the perceived need of Councils to strengthen their ability to respond effectively to the needs of the clients they were mandated to serve, and to insure the accountability of service programs to those clients. Second, as Councils gained knowledge and experience in the planning functions which they were created to perform, many of the priorities they adopted placed them clearly in an initiative posture, as opposed to their original more passive, advisory posture. Further, the problems for Councils in taking the initiative to implement their priorities required careful planning and utilization of resources, sustained by long range as well as short term technical assistance. In response to these perceived needs, a Conference was designed with the following goals:

1. To provide a core of Council members with assistance in considering the Council's potential as an advocacy-oriented group;
2. To provide assistance in developing action plans for implementing their specific priorities relevant to that potential;
3. To identify areas of further specific technical assistance needs for carrying out the action plan.

The Conference responded to the needs by providing specific training, related to individual requests for

technical assistance, in the context of the Councils' position as an initiative body. Ten State Councils were invited to participate in the Conference. Each State Council was to be represented at the Conference by a four-person team including: the Council chairperson, staff director, and two consumer-spokesperson Council members.

Activities designed to accomplish these goals and objectives included seminars, small group activities, large group presentations, and structured planning sessions. Relatively large blocks of free time were made available between the formal sessions to allow for the informal sharing of ideas and experiences. The evening sessions included a continuous display of advocacy related media materials available to Councils for use in public awareness programs (see Display A).

Prior to the Conference, each participant selected a seminar in which to participate, based on the content most related to the needs in facilitating the work of his or her Council. In most instances, the participants received background materials from the coordinator of the seminar they had selected. This had two results: (1) Conference participants arrived having already established contact with the staff with whom they would be working most closely, and (2) the selection of training areas served as a kind of needs assessment, identifying areas of Council priorities.

Unlike the seven seminars which were instructionally oriented, the ten small group activities were organized by state and oriented to planning and team development, applying the seminar training content to each state situation. The staff members assigned as resource persons to the small group activities were chosen so that none of the team members would have attended the seminar which that staff person coordinated. This allowed the staff member to act as an objective facilitator.

The members of each team represented various backgrounds, length of time as Council members, extent of involvement in program development, and conceptions of their role as Council members. The goal of the first

evening's small group activity was to utilize the richness of these variations around a task which could serve as a vehicle for the individuals to experience membership on a working team. A modified Force Field Analysis Exercise, described in Display B, is a somewhat loosely structured activity which provides for informal, interpersonal sharing as well as producing a product. The lists of assets and areas of weakness generated by the teams gave each team member a frame of reference for approaching the material in the second day's training (see Display C). The lists further served as a point of beginning in developing the implementation plan on the third day. An example is provided in Display D.

On the second day, each participant worked with representatives from other states in the training seminar which he had selected to attend. The training topics were: (1) Consumer Implemented and Evaluated Services Utilizing Limited Resources, (2) Regionalism and Organization of Councils with Attention to Region-State Interface, (3) Planning and Evaluation Data--Techniques for Data Collection: Alternative Approaches, (4) Accessing Federal and State Resources for Funding, (5) Media Utilization and Public Awareness, (6) Legal Issues: Litigation, Legislation, and Administrative Regulations, (7) Deinstitutionalization and Community Alternatives. An outline of the training provided in these seminars is included in Display E.

The rationale for the team members attending different training sessions included DD/TAS's attempt to provide maximum response to the needs identified by the Council teams. With limitations of time, it seemed more efficient to train four people in depth individually than to provide a general overview to a large group. A further objective was the development in each team member of an area of expertise which he could later share with the team and the entire Council. Each seminar was organized to provide opportunity for the participants to describe their own problems in planning implementation.

On the third day, each state team met with the resource person who had facilitated the Force Field Analysis Exercise, to integrate the material from the seminars

with the state's priorities to develop an implementation plan. The first portion of the day was given over to a brief presentation by each team member of the salient material covered in the respective seminars. This provided further opportunity for each team member to experience the role of leader and "expert". Each state team followed the same general planning format, which is shown in Display F. An example of the plans developed is included in Display G. A significant feature of the implementation plan, in terms of maximum long-term benefit of the Conference, was the naming of individuals to be responsible for specific portions of the planned implementation strategy. This provides accountability to one another and a contact person for future DD/TAS involvement with that state's activity in a given area.

The closing session provided an opportunity for each state to share its plan with other states, to gain closure on its own work, to think ahead for possible ways of using DD/TAS, and to join together in working with other states having related problems.

DISPLAY A

SCHEDULE OF ACTIVITIES

FIRST DAY

Opening Sessions: 7:30 - 9:00 p.m.

Ron Wiegerink: Overview of Conference Goals and Activities

Ron Neufeld: Councils for Developmentally Disabled as Advocacy Mechanisms

State Team Groups
facilitated by

DD/TAS staff: Force Field Analysis Exercise

SECOND DAY

Concurrent Seminars: 9:00 a.m. - 4:30 p.m.

Dan Davis: Regionalism and Organization of Councils with Attention to Region-State Interface

Paula Hammer: Accessing Federal/State Resources for Funding
Session 1: Public Assistance: SSI Module
Session 2: Revenue Sharing Module

Ron Thiele, Ron Neufeld, Jim Paul: Deinstitutionalization and Community Alternatives

Pat Trohanis: Media Utilization and Public Awareness

Rud Turnbull, Chris Pascal: Law and the Developmentally Disabled

Richard Surles: Planning and Evaluation--Techniques for Data Collection: Alternative Approaches

Ron Wiegerink: The Development of Guidelines for Involving Consumers in the Implementation of Service Delivery Systems for the Developmentally Disabled

Evening Session: 7:00 - 9:00 p.m.

Don Stedman: "Characteristics of Good and Bad Advocates"

Pat Trohanis and
Gary Richman: Media Review

Individual Consultation

THIRD DAY

Concurrent Planning Exercises: 9:00 a.m. - 4:30 p.m.

DD/TAS staff and
consultants: State Team Groups

Evening Session: 7:30 - 9:30 p.m.

H. Rutherford
Turnbull, III: "Through and Beyond the History of the Developmentally Disabled"

Frank Fusco: "Advocacy: A Consumer Perspective"

Pat Trohanis and
Gary Richman: Media Review

Individual Consultation

FOURTH DAY

Closing Session: 8:00 a.m. - 11:00 a.m.

Representatives from State Teams:	Brief Report of Each State's Imple- mentation Plan
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Ron Wiegerink:	Overview of Technical Assistance Available
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DISPLAY B

IDENTIFICATION OF FORCES THAT
FACILITATE OR RESTRAIN GOAL ACHIEVEMENT

Modification of the Force Field Analysis Process

Advocacy Problem:

It is difficult for a planning group with state and regional responsibility to stay in close touch with the problems of developmentally disabled citizens attempting to obtain necessary resources to lead full lives.

Advocacy Goal:

That Regional coordinators of the Developmental Disabilities Council understand, from the perspective of the developmentally disabled citizen, the needs of those citizens and take initiative on their behalf to have these needs met.

Instructions:

Most problem situations can be understood in terms of the forces which push toward improvement and the forces which resist improvement - in other words, facilitating forces and restraining forces.

As a group, discuss the problem and, (1) those affecting individual coordinators such as lack of information about the needs of developmentally disabled citizens, and (2) those affecting the Developmental Disabilities Council as an organization within State government such as their distance from the individual consumers. Use this distinction only as it helps you identify forces in your state - don't get bogged down in considering which category is more appropriate.

List as many as you can and record them on the flip

chart. At this point, do not worry about the priority of importance that should be assigned to each force. Be sure to keep a copy of the list developed.

DISPLAY C
LISTING FORMAT

Region _____

Facilitating Forces

Restraining Forces

Related
to
Individual
Council
Members

Related
to
the
Total
Council

DISPLAY D

EXAMPLE OF FORCE FIELD ANALYSIS

Facilitating

1. Active, competent Council membership present at Winter Park
2. Council members at Conference have linkages . . . skills to disseminate information
3. Council representatives at Conference represent disability areas of epilepsy, CP and MR
4. Persons at Conference work well together
5. As a group, have linkages that can provide clout
6. Have connections with competent and honest legislators
7. Have connection with In-coming Governor
8. Fair distribution of money
9. Existence of an effective program evaluation system
10. Regional councils for information dissemination and program development

Restraining

1. Territoriality in State agencies
2. Lethargy in Council members
3. Top agency people not present at meetings (representatives cannot speak for agency)
4. Lack of balance in delivery systems and resources Council attends to
5. Geography--spread out and representation difficult
6. Bureaucrats in agencies not sufficiently responsive to consumer organizations
7. Bureaucrats not aware of consumer needs
8. Staff turnover
9. Lack of innovative ideas
10. Preoccupied with funding projects
11. Unknown to the Governor
12. Urban emphasis without attention to rural needs
13. Lack of organizational connection between state and regional council

DISPLAY E

SEMINAR OUTLINES

Consumer Involvement Module

Goal: To develop an understanding of the professional functions that consumers can assume and to develop strategies for enabling consumers to take an active role in service delivery systems.

Agenda:

1. A rationale for consumer involvement
2. An overview of the Regional Intervention Program (RIP) of Nashville, Tennessee, slide show and discussion by Director
3. An in depth look at the functions of consumers in the Regional Intervention Program -- from training to evaluation
4. A media presentation of RIP components -- individual tutoring, generalization training, language classroom
5. A look at the consumer training materials
6. Development of standards, guidelines and grant review procedures which would lead to implementation of consumer participation in programs for the developmentally disabled

Seminar coordinators: Ronald Wiegerink
Iris Buhl

Advocacy and Regionalism Module:

Goal: To provide participants with an understanding of the concept of regionalism as a governmental structure having implications for the quality of service to developmentally disabled people.

Agenda:

Part I

1. Overview of the Module
2. Introduction to Regionalism and Advocacy
3. Status of State Regionalism Programs and Advocacy Policies

Part II

1. Advocacy as a Value: Parent Group Organizing
2. Perceptions of Advocacy and Structures: Organizational and Client Perspectives -- An Exercise

Part III

1. Group Work Simulation on Regional and State Issues
2. Discussion on the Organizational Implications and Alternatives Available to States

Part IV

1. Total Group Review and Report Back

Seminar coordinators: Dan Davis
Ed Humberger
Elizabeth Bauer

Planning and Evaluation Module

Goal: Provide a framework for planning which acknowledges the complexity of planning for the Developmentally Disabled but which encourages the initiation of goal directed action by the council.

Objectives:

1. Participants will review and understand a model for council planning.
2. Participants will discuss the model in light of major common tasks of DD councils and staffs.
3. Participants will successfully use the model in planning to meet a goal established by the group.

Agenda:

1. Develop group consensus on key planning terms
2. Develop definition of key planning concepts
3. Introduce Model for Council Action
 - A. Rationale & Alternatives
 - B. Design for Council Planning
4. Provide an example of eight planning elements
5. Provide a case history of development of planning elements over time
6. Provide a situational set for use of model by group
 - A. Group establishment of beliefs and priorities, goals and objectives
 - B. Group development of possible strategies for other

six elements

Seminar coordinators: Richard Surles
Carolyn Cherington

Resource Acquisition Module

Part I

Public Assistance: SSI Module

Goal: To train participants in the intricacies of the Federal-State public assistance program, including both mandatory and optional provisions relating to assistance payments, social services, and medical assistance.

Objectives:

1. Identify and describe specific provisions of the public assistance program in their state (mandatory and optional).
2. Identify decision points to improve the public assistance package currently available in their state (ie. optional services, optional supplements).
3. Act as an advocate for the developmentally disabled person who is inappropriately handled in the public assistance program - (ie. eligibility determination, service referrals).
4. Move to amend a state social service plan to include special or priority services to the developmentally disabled.
5. Develop a purchase of service contract with a social agency.

Seminar coordinators: Paula Hammer
Jennifer Howse

Part II
Revenue Sharing Module

Goal: To train DD Councils to optimize state and local revenue sharing funding for the developmentally disabled.

Agenda:

1. Overview of General Revenue Sharing Program
 - A. Federal Law
 - B. Federal Guidelines
 - C. Trends to Date--how is the money being spent?
2. Revenue Sharing as a Funding "Mechanism" proposed for Other Programs
3. Techniques in Assessing State Revenue Sharing Funds for the Developmentally Disabled (State Rep.)
4. Techniques in Accessing Local Revenue Sharing funds to Benefit the Disabled (Local Rep.)
5. In small groups
 - A. The researching monitoring tasks
 - B. Preparing and presenting a proposal for revenue sharing funds
 - C. Organizing support for your proposal
 - D. Influencing activities
6. Mock Hearing

Two small groups present proposals to Mock County Board of Commissioners (Consultants, DDTA Staff)

Seminar Coordinators: Paula Hammer
Jennifer Howse

Public Awareness Module

Goal: To develop a framework for understanding public awareness programming as a planned advocacy activity and to develop strategies for program planning.

Agenda:

1. Overview of Public Awareness: Foundations of Public Relations
2. Message Design and Audience Considerations
 - A. Research and Assessment
 - B. Setting public relations goals and objectives
3. Delivery Strategies and Options
 - A. State of the Art within the DD movement
 - B. Examples of potential opportunities which DD could capitalize on
 - C. New opportunities
4. Implementation of a Public Awareness Campaign
5. Evaluation of Public Awareness Efforts
6. Wrap-up
 - A. Preparation for Team Reporting
 - B. Individual Consultation

Seminar coordinators: Pascal Trohanis
Emanuel Raices
Gary Richman

Law Module

Goal: To provide information so that Developmental Disabilities Councils may develop at-home goals for legal advocacy.

Agenda:

1. Introduction -- Overview of Constitutional issues (due process and equal protection) and recent litigation (rights to education and treatment)
2. Introduction -- The "Law" as a multifarious discipline -- judicial, legislative, and administrative developments; volunteer and private group efforts.
3. Right to Education; Tracking and Sorting; early intervention; "appropriate" education; due process in assignments, classification, exclusion, and placements; claims to special ("appropriate") and compensatory education; fiscal impacts; infrastructure rearrangements.
4. Right to Treatment; in-institution rights to treatment; out-of-institution rights to treatment; patients' rights in the institutions (privacy, etc.); deinstitutionalization as the least restrictive alternative placement; treatment that might be unwarranted (aversive therapy) and least restrictive treatment means; non-compensatory labor; right to humane conditions; Patients' Rights Legislation (NC) administrative guidelines to patients' rights; group homes' establishment and planning; in-institution advocacy models.

Seminar coordinators: Chris Pascal
H. Rutherford Turnbull, III
James L. Paul
G. Ronald Neufeld

Deinstitutionalization and Community Alternatives Module

Goal: To help participants be prepared to assist in conceptualizing and planning implementation of deinstitutionalization activities of their DD Council.

Agenda:

1. Introduction of Participants, Goals and Objectives
2. The Evolution of Institutions and the Process of Institutionalization
3. Institutions and Change
 - A. A Frame of Reference
 - B. Resistance to Change
 1. The Child Advocacy Center
 2. Governor's Commission on Child Advocacy
 3. Institutional Advocacy Designs and Conflict
 - C. Administrative Reactions
 - D. Institutional Initiatives to Change
 1. Evaluation through Tracking
 2. Staff Advocacy Design
 3. The Full-Time Advocate
 4. Human Rights Committee
 5. Patients' Rights and the Law Study
 - E. Institutional Initiatives in Community Resource Development
 1. Infant Stimulation
 2. Parent Training
 3. Bringing It All Back Home
4. Communities and Deinstitutionalization

- A. The Meaning of Community
- B. Resocialization and Deinstitutionalization
- 5. People and Deinstitutionalization (Role Play)
 - A. Problems in Service Delivery
 - 1. Organizational Perspective
 - 2. Consumer Perspective
 - B. Need for Advocates
 - C. Reconciliation: A Balance of Organization - Person Satisfaction
 - 1. Ecological Planning
 - 2. / Concept of Fit
 - 3. Advocacy Mechanisms
- 6. Organizational Support Structures
 - A. Geographic Boundaries and Citizen Involvement
 - B. Group Home Boards
- 7. Communication and Monitoring
 - A. CASP Manual
 - B. Utah Public Hearing Design
 - C. County Communications Agents
- 8. Training
 - A. Staff Exchange Program
- 9. Components of a Comprehensive Community Program
 - A. Programmatic Outline for Deinstitutionalization
 - B. ENCOR

/ C. Group Homes

10. Summary and Development of Reports

Seminar coordinators: James L. Paul
G. Ronald Newfeld
Ronald Thiele
Jo Lowe

DISPLAY F

GUIDELINES FOR ACTIVITIES AND
INFLUENCE IMPLEMENTATION

Taking the five or so priorities that your team has developed, the work can be divided into two sections (1) activities or steps, including resources, to accomplish the priorities and (2) how to go about implementing those activities.

In order to get at the above, we suggest the following outline for work:

- (1) take each priority, one at a time, and each team member individually list what activities, and resources it will take to effectively address that priority.
- (2) share those lists with each other to be sure each understands the other's list.
- (3) informally discuss each other's list and, by consensus, decide which activity(ies) makes most sense for your state.
- (4) do this for each priority.

This completes the first half of the work.

The second half may go this way:

- (1) take the activity list for the priorities, one at a time, and informally discuss the alternatives for implementing that activity, including how to influence the council and any other relevant individuals and/or organization(s).
- (2) give particular attention to which team member will do what to implement the activities. Give role assignments and be accountable to one another as a team.

SUMMARY WORKSHEET FOR ACTIVITIES AND RESOURCES

	Activity(ies)	Resources Available and/or needed
Priority 1		
Priority 2		
Priority 3		

EXAMPLE OF A TEAM PLAN

Priority #	Activities	Resources	Implementation Strategy	Individual Roles
The Council will expand its legislative and legal roles as they pertain to the developmentally disabled.	1.a. Examine and make recommendations for possible legislation, zoning, and other regulations as they affect community alternative programs.	1.a. State Human Rights Commission	1.a. Establish a Council Ad-Hoc Committee on Legislative and Legal Activities.	1.a. Team (including Chairperson and Staff Planner) designated a Committee Chairperson at Winter Park.
	1.b. Review current legislation and/or statutes related to institutionalization.	1.b. UAF	1.b. Committee will be formulated in Winter Park.	1.b. Committee Chairperson, Council Chairperson and Planner would contact other Committee members.
	1.c. Monitor statewide client tracking system to insure legal rights of citizens.	1.c. DD Council (and \$15,000 for additional staff, etc.).	1.c. Committee will convene for its first meeting approximately one month after Winter Park.	
	1.d. Establish legislative and legal aid resources for consumers, advocates, and government employee.	1.d. Local law school		
		1.e. Volunteer groups		

1. The first part of the document discusses the importance of maintaining accurate records of all transactions and activities. It emphasizes that proper record-keeping is essential for transparency and accountability, particularly in financial matters. The text suggests that organizations should implement robust systems to track every aspect of their operations, from procurement to sales.

2. The second part of the document addresses the challenges of data management in a rapidly changing environment. It highlights the need for flexible and scalable solutions that can adapt to new technologies and evolving business requirements. The author argues that investing in modern data infrastructure is crucial for staying competitive and making informed decisions.

3. The third part of the document focuses on the role of leadership in driving organizational success. It stresses that effective leaders must inspire their teams, set clear goals, and foster a culture of innovation and collaboration. The text provides several practical tips for developing strong leadership skills, such as active listening and open communication.

4. The fourth part of the document explores the impact of external factors on business performance. It discusses how economic conditions, market trends, and regulatory changes can influence an organization's strategy and outcomes. The author advises businesses to stay vigilant and adaptable, regularly assessing their position in the market and adjusting their plans accordingly.

5. The fifth and final part of the document offers concluding thoughts and recommendations. It reiterates the key points discussed throughout the paper and encourages readers to take action on the insights provided. The author concludes by expressing optimism about the future of business and the potential for growth and innovation.

APPENDIX 2

APPENDIX 2

DD/TAS Conference Staff

Dan Davis	Gary Richman
Paula Hammer	Donald Stedman
Jo Lowe	Richard Surles
Ronald Neufeld	Pascal Trohanis
Chris Pascal	Ronald Wiegerink
James Paul	Grant Wolslagel

Conference Consultants

Elizabeth Bauer	Ed Humberger
Iris Buhl	Emanuel Raices
Carolyn Cherington	Ronald Thiele
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Conference Participants

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Georgia:	Carol Frank Tony Long
Iowa:	Clell Hemphill Dudley Koontz Wanda Schnebly Margaret Westerhoff
Maryland:	Erna Hoig Karin Lapidus William Lowman Sheridan Neimark
Minnesota:	Mary Ann Jensen Toni Lippert Ronald Sandness

Minnesota continued:

Roger Strand

Oregon:

Allison Belcher

Nancy Jaggar

Jerry McGee

Rhode Island:

Frank Fusco

William Donovan

Richard MacMullen

Frank O'Lean

South Dakota:

Doris Bruns

Arleen Nelson

Thomas E. Scheinost

Wyoming:

J. Darryl Cooper

Sally Vanderpoel

R. W. Vaughn